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PROFESSIONAL AND CLIENT CHOICES IN CRITICAL SITUATIONS.

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DESCRIPTORS- *REHABILITATION COUNSELING, *PHYSICALLY HANDICAPPED, *ATTITUDES, SPECIAL HEALTH PROBLEMS, *INTERACTION,

THIS REPORT DESCRIBES A STUDY OF PROFESSIONAL--CLIENT RELATIONSHIPS IN THE REHABILITATION OF THE PHYSICALLY HANDICAPPED. THE PURPOSES WERE--(1) TO INVESTIGATE VIEWS HELD BY PROFESSIONALS AND CLIENTS ABOUT "CRITICAL SITUATIONS" STEMMING FROM A CLIENT'S DISABILITY, (2) TO DETERMINE CONDITIONS UNDERLYING THESE VIEWS, AND (3) TO PROVIDE HELPFUL INFORMATION FOR THE TRAINING OF STUDENTS CONNECTED WITH REHABILITATION. TAKING PART IN THE STUDY WERE THREE GROUPS OF SUBJECTS, MOST OF WHOM HAD SPENT TIME IN OTHER INSTITUTIONS. THEY INCLUDED--(1) 20 ADULT PATIENTS IN A REHABILITATION HOSPITAL, (2) 20 PROFESSIONAL STAFF MEMBERS, AND (3) 20 STUDENTS IN TRAINING FOR VARIOUS HELPING PROFESSIONS. THE SUBJECTS WERE ASKED FOR INFORMATION THROUGH EXPERIMENTAL INTERVIEWS AND WERE GIVEN INFORMATION TO MAKE A DIALOGUE POSSIBLE BETWEEN THEM AND THE EXPERIMENTER. THE DATA WAS ANALYZED WITH EMPHASIS ON ITS QUALITATIVE ASPECTS. THE STUDY LED TO THE FOLLOWING CONCLUSIONS--(1) SOME SITUATIONS CAN BRING ABOUT DIFFICULTY IN THE RELATIONSHIP BETWEEN PROFESSIONAL AND CLIENT, (2) THESE DIFFICULTIES CALL FOR CAUTION IN HANDLING, NOT THE ELIMINATION OF DIFFERENCES, AND (3) SOME DIFFERENCES IN VIEWPOINT BETWEEN PROFESSIONAL AND CLIENT CAN BE CONSTRUCTIVE. (RD)

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PROFESSIONAL AND CLIENT CHOICES IN CRITICAL SITUATIONS

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FOREWORD

This report of work done under a planning grant for a study of professional-client relationships in the area of rehabilitation, is designed to accompany a forthcoming proposal for a full-scale study. It begins with a very brief resume of purpose and procedures. The presentation was made as non-technical as possible in the hope that it will be read by professionals with very different backgrounds.

I wish to thank Dr. Tamara Dembo and Dr. Beatrice Wright, who generously donated their services as consultants in order to promote research in the area of professional-client relationships.

Schwab Rehabilitation Hospital, staff and patients, whole-heartedly co-operated in the undertaking. It should be noted that most of those who served as subjects had spent time, as patients or professionals, in other institutions, so nothing said can be construed as a reflection upon the institution which was the setting of the study.

Gloria Leviton
October, 1967

TABLE OF CONTENTS

Page

Ch I. Purpose and Procedure 1

- Purpose 1
- Meaning of the Term "Critical Situation" 1
- Approach in the Planning Period 2
- Methodology 2

Ch II. Personal Involvement Versus Emotional Neutrality 7

- Over-all Preference of Subject Groups 8
- The Case for Personal Involvement 10
- Practical Limitations to Involvement 15
- The Case for Emotional Neutrality 18
- Current Teaching Regarding Involvement and Emotional Neutrality 24
- Preliminary Recommendations 25
- Summary 29

Ch III. Hope and Reality 31

- Over-all Preference for the Hopeful or Realistic Approach 31
- The Case for Hope 35
- The Case for Reality 40
- Manner of Communicating Information 53
- Information Giving and Inter-professional Relationships 55
- Preliminary Recommendations 57
- Summary 60

Ch IV. Independence and Dependence 62

- Reasons for Positive Evaluation of Independence 64
- Reasons for Allowing Dependence 80
- Positive Aspects of Dependence 86
- Unacknowledged Dependency Needs 93
- Preliminary Recommendations 95
- Summary 99

TABLE OF CONTENTS

Page

Ch V. Other Critical Situations; Suggestions for Further Research 100

- Control Vested in Professional or Client 101
- Safety-first Versus Taking Risks 104
- Candidates for Rehabilitation 105
- Placement after Discharge 109
- Investigation of Determinants Underlying Reasons for Choices 113
- Critical Situations in Other Settings 116
- Investigation of Views Promoted by Teaching Personnel 117
- Long Range Research Programs 117

Appendix I. Subject Characteristics 119

Appendix II. Approach to Subjects and Interview Schedule 122

Appendix III. Frequency of Topics Spontaneously Brought up by Subjects 133

Publications Cited 135

CHAPTER I

Purpose and Procedure

Purpose

The purpose of this pilot study was to investigate conflicting views, as well as agreement in views, between professionals and clients about critical situations stemming from a client's disability, and to determine conditions underlying these views. The investigation, in addition, had the practical aim of providing information which might be helpful in training students of various professions contributing to rehabilitation.

Meaning of the term "critical situation"

We call those situations "critical" in which:

1. An important problem concerning the client faces the client and/or the professional. (For example, it may be hazardous for a cardiac patient to continue in his present occupation.)

2. Alternative and defensible solutions to the problem are possible. (In the above example: There may be reasons for choosing to take the risk of continuing in the same job, or, instead, "playing safe" may be preferred.)

3. Conflict occurs between professional and client because they choose different alternatives, or in the individual, because a decision between the two alternatives is difficult.

It follows from the meaning of critical situations given above that not all difficulties between professionals and clients constitute critical situations. For example, if a nurse openly shows her disgust to a stroke patient who has lost bowel control, this may negatively affect their relationship. This is not a critical situation because the behavior of the nurse is not defensible, in the sense that some professionals would recommend and even argue for this kind of behavior.

Critical situation is a concept of the investigator, arrived at by juxtaposition of the recommendations of several clients and professionals. A particular pair may share the same viewpoint and thus no conflict would exist between them. A given individual may find one alternative so unacceptable that it is immediately discarded and so no conflict exists in that person. Conflict, then, is not a necessary part of every instance of a situation usually regarded as critical, but it is an integral part of the concept.

Approach in the planning period

In approaching these problems a planning period was judged to be necessary: first, to try out methods of investigation and analysis; second, to determine a number of areas in which critical situations can arise and which of these seem most fruitful for further study; third, to seek testable hypotheses by exploring particular critical situations qualitatively, especially as regards:

a. Differences in views between professional and clients regarding recommended solutions.

b. Determinants underlying choices (for example, what specific values or needs, what beliefs or items of knowledge are invoked as supporting reasons for choice of alternatives).

c. The kinds of conflict that can arise in the individual (professional or client).

d. Whether what is currently taught to students leads to resolution, leaves the conflict unresolved, or even exacerbates difficulties in the professional-client relationship.

e. Possible ways of resolving differences between the partners, or ways of diminishing conflict in the individual.

Methodology

Subjects: In keeping with the purposes outlined above, three groups of subjects were chosen: 20 adult patients in a rehabilitation hospital, 20 professional staff members in the same setting, and 20 students in training for various helping professions. Descriptions of these subjects is given in Table I in the Appendix. It will be seen that, within the groups, diversity was stressed rather thanhhomogeneity. This was seen as an asset in an exploratory investigation.

Procedure: A special type of experimental interview was designed, and was modified during the pilot period. Some special characteristics of this interview should be noted.

First, much attention was given to the way in which the problem under investigation was introduced to the subject. It was considered desirable that he clearly understand the purpose of the research and the potential usefulness of his contribution. It was pointed out that only persons who face such situations are in a good position to supply the information needed. It was explained that this was a planning year, and the subject was asked to be a co-investigator and to help in deciding which problems require investigation.

Secondly, the subject's position as a partner in the research was emphasized by beginning the interview with a topic which he, not the experimenter, chose as an important one. Throughout the interview, his leads were followed. Although the experimenter had an interview schedule as a guide so that particular areas could be covered, the order and formulation of questions was changed, whenever necessary, to take account of what the subject had said.

The initial question on each topic was as general as possible to allow maximum room for the subject's own interpretation. Subsequent questions were more specific to insure that interviewer and subject understood each other clearly. There were many follow-up questions concerning the meaning of words used by the subject, and many questions of the "why" variety. It had been explained at the outset that not only his opinion of which course to pursue, but also his reasons for choice were important.

To insure a comfortable relation between experimenter and subject and to minimize the necessity for defensive guarding, the experimenter gave information as well as soliciting it. The situation thus became a dialogue between two persons with mutual concerns, not one putting the other "on the spot". For example, after hearing a subject's opinion, the experimenter might tell him what another person had said on the same topic. This had an additional advantage: acceptance or rejection of a different point of view gives clues to what might facilitate change or what resistances to change might exist. This will be important for our long-run purposes.

The way in which subjects were approached and sample interview questions, are given in Appendix II.

In analyzing the data, emphasis was placed upon its qualitative aspects because of an interest in the scope of meanings of each situation, rather than in frequency of occurrence. Clarification of what may be desirable to quantify was seen as an important preliminary step.

The first task of analysis was to determine what "topics of concern" were spontaneously mentioned by subjects, either in response to the first question inviting them to suggest problems worthy of investigation, or later in the interview. In Table II, (Appendix III) the list of these topics is given. Not all are, at present, seen to be critical situations,* and not all fell within the scope of the present study. (For example, interdisciplinary problems concern the relationship of professionals with each other, not relationships of professionals with clients.)

The critical situations chosen for intensive analysis were the following:

1. Whether the professional should attempt to maintain an attitude of emotional neutrality toward his patients or, instead, become personally involved with them.

2. Whether to take a hopeful or a realistic approach to the matter of giving information to patients regarding their present physical condition and prospects of improvement.

3. Whether to stress independence with regard to physical tasks as much as possible, or whether (and under what circumstances) to permit or even encourage dependence.

4. Whether (or in what areas) control should be vested in the professional, or whether more opportunities for decision-making should be given to patients.

5. Whether it is best always to "play safe" or whether, under some circumstances, one can justify letting the patient take some risks.

6. Whether time and rehabilitation resources should be invested in patients who can be only slightly upgraded, or whether preference should be given to those who are most likely to profit therefrom.

7. Whether a patient should return to his home after discharge from the hospital, whenever this is possible, or whether alternative placement should be sought.

The further tasks of analysis - comparison of patients and professionals with respect to choice of alternatives and reasons for choices - will be illustrated in the three succeeding chapters.*

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*The determination of what is a critical situation and what the boundaries of the critical situation are, is itself a matter which requires analysis. As will be seen in Chapter V, the superficially very different problems concerning optional surgery and time of "lights out" in hospitals, can both be seen as subsumed under the heading "control and decision-making."

We want to emphasize that the tables which follow are given primarily as a summary for the reader. The numbers therein are given only so that the reader can judge for himself the basis for the investigator's statements. No claim is made that measurement has been achieved or that the sample is representative. Also, since questions were not identical, calculations of significance of differences between groups is not warranted. The same characteristics of the interview, discussed above, which add greatly to our understanding of the situations and which are invaluable from the standpoint of generating hypotheses, preclude the use of sophisticated statistical techniques. Numbers so derived cannot be used as definitive evidence for or against the hypotheses.

It will be noted that in spite of these reservations, recommendations have been given in the chapters which follow. The recommendations are, of course, tentative and themselves must be tested and clarified in later investigation. They are, for the most part, however, not dependent upon numerical results. They are a consequence of the qualitative study--the understanding of the meanings of the critical situation. The fact that a particular situation can bring about difficulty in the relationship between professional and client, even before we know how often this is likely [illegible] occur, led us to the belief that, even at this early date, it would be worthwhile to point out to professionals those problems which call for caution in handling. Caution in handling is what we think is called for, not eliminating differences. We would not wish to imply that all differences in viewpoint between professional and client have negative effects. Some differences can be constructive and may be precisely what is needed to help a patient toward adjustment. (See, for example, the discussion in Chapter III of changing content of hopes.)

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*In later reports we will discuss in detail: (a) The rationale for using everything a subject says on a topic in determining his over-all preference for one alternative, instead of his initial response which is least influenced by the experimenter. (b) The reliability of judgment of over-all preference, and reliability of categorization of reasons for choice. The chapters which follow are concerned with definitions of categories. Now that these have been defined, it will be a relatively simple matter to have two persons make independent judgments of the categories involved in each subject's reasons for choices. The percent of agreement between the two judges can be calculated. (c) The handling of additional comments on the topic which are not reasons for choice.

A final word about frequency: Even if only a few professionals hold viewpoints which are unacceptable to clients, it must be remembered that every professional serves many clients, thus multiplying the occasions of difficulty in relationships. Furthermore, if such a person were to teach or to assume a leading position in an institution, these viewpoints would be transmitted to others and perhaps would influence the whole atmosphere of the institution.

CHAPTER II

Personal Involvement versus Emotional Neutrality

Although not posed as a critical situation, there are references to personal involvement and to emotional neutrality in the existing literature*. The fact that so many of our subjects spontaneously brought up the problem** also indicates that it is already known and is a matter of concern. The contribution of the present study lies in the juxtaposition of patient attitudes with professional views, and scrutiny of the many qualitatively different meanings which the topic has. Most important was the attempt to understand the reasons for choices, for this is a necessary step in any attempt to bring about whatever change might be required.

The situation is one which faces the professional, not the client. Even though the problem may be a consequence of the handicapping condition, it is the professional who must decide whether to permit himself to become personally involved with his client or whether to maintain emotional neutrality. A physical therapist, for example, chooses the first alternative:

> Here you can be a patient's friend as well as his therapist.

A medical student prefers the second alternative:

> We're not here to be friends particularly... It's more important any time you're going to treat a patient over a long time, to maintain--I don't think aloofness is a good word--but maintain your position.

The client has a point of view on this, of course. He also makes recommendations about which alternative is the better course to follow. For example, this woman patient said:

> Sometimes you'll meet a therapist that is very cordial, but most of them are so business-like, you know, because they just take it for a matter of fact--it's a job and they're doing it. It's not like--well, you've got to have the attitude of meeting people and knowing them...and liking

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*See, for example, Kutner (8) and King (5).

**See Table II, Appendix III.

> to help them a little bit... They're helping in their way but they don't help them all ways... It has to be a little bit more personal. You have to take the individual.

The implication here is that the patient's trouble is not limited to his disability, but spreads over into other areas of his life. Therefore, the expert should not be limited to giving of his specialized knowledge. His giving must also spread over the whole psychological relationship with his patient.

Over-all Preference of Subject Groups

The over-all preferences of the subject groups for involvement or emotional neutrality and the number whose preference is unclear is shown in Table III. As indicated by the discussion in Chapter I, only a limited significance is attached to the quantitative data. At the same time the numbers are not meaningless. Since no patients, at least in this group, advocate neutrality, and some professionals do, difficulties can arise if those who advocate neutrality have extensive contact with patients.

A word about the "Preference Unclear" column: The patients included here, for the most part, are those whose discussion of the topic indicated an attempt to understand the position of the professional. Therefore, they excuse the professional for not becoming more involved; thus:

> There are so many patients, you can't expect a great deal. They do what they can. You really don't expect anybody to become personal.

This certainly is not the same as advocating neutrality. Nor does it appear to indicate conflict about this issue.

The professionals who are included in the "unclear" category are often those whose conflict is so great that this made determination of preference difficult. Or they were students who dimly felt that some balance between the two alternatives was possible but who were puzzled as to how this could be achieved. For example:

> There's definitely an emotional neutrality that you can attain but it's very difficult, I feel. Sometimes we tend to be not enough... I think most of us that are still students, being very keyed up over a situation, being

Table III

Number of subjects who indicated over-all preference for personal involvement or for emotional neutrality, and the number whose preference is unclear.

Subject-Class	Pro-involvement	Pro-neutrality	Preference Unclear	Total
Clients	13	0	4	17
Professionals	11	5	3	19
Students	9	4	6	19
Total Subjects	33	9	13	55*

*Three client subjects, one professional, and one student, were not questioned on this topic.

> very emotional - and when we try not to be, people think, "Well, she isn't at all; she doesn't care". And it takes a while to learn to be emotional and unemotional at the same time.

It is the standpoint of the investigator that it would not take as long to learn to achieve the balance sought if students could be thoroughly acquainted with the patients' viewpoint on this matter, and with reasons given by professionals in favor of a different viewpoint.*

The Case for Personal Involvement

Emotional neutrality does not mean coldness. By definition, neutral means neither warm nor cold. And in general one would not expect coldness to be characteristic of those who elected to go into the helping professions. However, they may be judged to be cold by patients. For what the patient recommends is personal involvement on the part of the professional. What he wants is interest shown in himself as an individual, concern about his needs, and warmth instead of a matter-of-fact approach.

Table IV shows the kinds of reasons given for the involvement side of the issue. The numbers refer to the number of subjects who used a category at least once. The reasons include meanings or implications of involvement or emotional neutrality, and the consequences which are presumed to follow from the alternative courses of action.

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*Most of what we shall discuss in this chapter deals with the kind of difficulties that arise because of misunderstandings of what each partner wants on the overt level. These are the difficulties which are most easily avoided and hence could be cleared up first. There are many levels which exist, and some of our future work will deal with individual value systems--a second level, but not yet involving the unconscious.

We do not imply that, because something is more covert, it necessarily causes greater difficulties in the relationship. For instance it was said that sometimes professionals become involved with patients to gratify their own needs (i.e., they want to be important to the client; they want to be seen as benevolent, helping persons). We must then ask, is this at the expense of the patient? If they are doing the right things for the wrong reasons, difficulties need not arise.

Table IV

Categories of reasons in favor of involvement.

Category	Number of subjects using a given category at least once			
	Clients	Professionals	Students	Total
1. Emotional satisfaction of client (means warmth, interest, makes you feel good, etc.).	12	10	13	35
2. Devaluative implications of non-involvement. "Treating like a thing instead of a person."	3	4	5	12
3. Rehabilitation progress:				
a. Involvement leads to increased motivation of patient	1	2	3	6
b. Involvement leads to better communication between partners	3	0	1	4
c. Involvement is part of good care; non-involvement leads to error; my specialty requires involvement	1	3	4	8
Total reasons for involvement*	20	19	26	65

*These numbers will not correspond to those in Table III because subjects give more than one reason for a given course of action and can give reasons on both sides of the issue.

1. Emotional satisfaction of client

One reason given in favor of personal involvement is that it is satisfying per se. Patients often gave as a "reason" some approximate synonym of involvement. They say it means or implies friendliness, cordiality, caring, concern. Or they might add that "it makes you feel good" or "cheers you". Sometimes we infer this category of reason from a patient's complaint. This stroke patient, for example, believes:

> Every patient feels neglected in some way... This is what they should take care more of - the small things; the big things they know... Some are nice - some seem a little unfriendly - but may be it's the policy. You sometimes get the feeling they don't care too much.

But what patients praise leads to the same inference. For example, a young paraplegic stated, when asked whether he agreed with some who objected to impersonality:

> No, I don't think they're impersonal. I get along pretty well in most cases. It's not just like a routine thing... There's my therapist and she's got a job to do. And I'm the patient and she's going to show me; but that doesn't make a cold wall between us. I think I get along more or less just like a friend... I kid around a lot and they go along. So for me they're not cold and indifferent.

Turning now to the professional side, we find instances of advocacy of involvement in the sense of warmth and interest in the individual. A recreation therapist volunteered this comment:

> Another thing that disturbs me very much is that most therapists tend to concentrate on a disability that is related to their particular area and thus disregard individuals as a whole. They don't really consider him, his needs, his interests, his personality... And they have a tendency to be somewhat impersonal and cold, maybe, and thoughtless, perhaps.

And a medical student defines involvement in terms of the first category:

> Emotional involvement has got to be, as I see it, in terms of the patient thinking you care about him. If the patient thinks that

> you feel he's just another patient and another fifteen minutes out of the eight hours, this is very bad... He has to be treated as an individual. (Show) that you sincerely sympathize with his situation, and you sincerely wish for him to get better.

Indeed, as can be seen in the table, the professionals and students do not differ much from patients in frequency of use of the category labeled "emotional satisfaction". The difference is that the remarks of the former groups are diluted by the proportion of negative reasons. For while this first category comprises 40% of all patient reasons for evaluations, pro and con, for the professionals and the students, this category accounts for 24% and 26% of evaluative reasons respectively.

2. Devaluative implications of non-involvement

The second category of reasons in favor of involvement has to do with status and devaluation. Being sensitive to the devaluative attitudes which normals have towards the disabled (and which he may have shared or even still holds*), a patient can interpret lack of personal involvement, lack of warmth, as an indication of devaluation. He needs assurance that he is just as worthy a human being as the non-handicapped person is. It is this devaluation aspect which is stressed in this excerpt from the record of a paraplegic who is also president of a patient club in the hospital:

> One of the other things that we (the club members) are working on, is the staff treating the patient...not only as a patient but as a person as well. As a human being instead of just a thing, just a machine or something, treating a patient like someone with feeling. And (with) kindness and gentlenens and respect.

Again there were no noticeable differences in frequency of this category of response among the subject groups. But although these words of a speech therapist are very similar to those of the patient just quoted,

> It is degrading...to be treated just as another body rather than a person. (Or on ward rounds) not as a person but just an object to be discussed,

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*See "Adjustment to Misfortune", (3).

the context is remarkably different. She had just noted a failure on her own part to take this feeling of degradation into account, and explained it as follows:

> It is easy to become a little mechanical, go through the same type of therapy procedures with every patient and pick this one person up and put somebody else in his place. It's just easy to forget the personal aspect.

The difference which context can make is one reason for stressing qualitative rather than quantitative analysis.

3. Involvement and rehabilitation progress

The remaining categories of reasons used by those favoring more involvement, emphasize rehabilitation progress. The answers are too few and scattered to permit comparisons between groups. The various reasons are similar in that involvement is seen as the means toward the end which both parties are seeking to achieve. For example, a good relationship between patient and professional helps toward the goal of independence. A paraplegic patient says:

> They should be very warm toward the patient, instead of trying to keep a distance, because this makes a patient less willing to help himself.

An O.T. described the positive effect of surprising an apparently unmotivated patient with a birthday cake. She added that, though it doesn't have to be that dramatic, "many times if you give the patient something, they'll work ten times harder for you."

The feeling of this patient is that lack of involvement leads to lack of communication:

> Some doctors take like a personal interest in you. Others are kind of cold, and you're afraid to ask them about anything... There's a couple of nursing staff that could unbend a little bit and have a different feeling... you wait for a different shift to come on to ask for something which is necessary.

This patient, also, when asked about involvement, replied with a comment on communication:

> I did have that opinion at one time, that I and the staff weren't quite communicating as we should... The patient knows quite a bit about his problem that could be helped

> if the staff would stop and listen.

Since a lack of communication between professionals and patients may lead to misperception of the needs of patients, it can impede rehabilitation progress.

In extreme instances, lack of involvement can even lead to errors, with serious consequences for the health of the patient. A nurse in a supervisory capacity mentioned instances known to her:

> All they look forward to is to get off and get their pay check...and they can forget some of the most vital things about patients... They forget to tell you... And they should notice every sign like that. It is vital that the head nurse know these things.

Sometimes professionals felt that their particular discipline requires involvement. Thus a psychologist stated:

> Deep involvement is needed in therapy to provide the patient with a comfortable relationship.

Another professional felt that:

> As recreation director, I can't keep at a distance; I must be a buddy, and informal and permissive.

But the pro-involvement attitude is not limited to certain professions. There were representatives of every discipline sampled who felt as this student nurse did:

> The more you get involved, the better you understand your patient.

We must look elsewhere for the forces hindering professionals from giving the patient what he wants. Table V lists some of these forces.

Practical Limitations to Involvement

One of the reasons sometimes given for professionals not becoming more involved with clients, is simply the practical fact that professionals serve a large number of clients and, therefore, the time they can spend with any one client will be limited. This cannot be fairly included in the case for emotional neutrality,

Table V

Reasons given for limiting involvement or in favor of emotional neutrality

Category	Number of subjects using a given category			
	Clients	Professionals	Students	Total
Practical limitations to involvement:				
Number of patients or limited time of professionals prohibits greater degree of involvement	5	3	2	10
Reasons in favor of emotional neutrality:				
1. Objectivity desirable for clients' benefit. Professional better able to see long-run goals.	1	7	9	17
2. Neutrality leads to better control.	0	1	4	5
3. Objectivity as a psychic protection for professional.	2	7	8	17
4. Other reasons (see text)	2	4	1	7
Total reasons for emotional neutrality	5	19	22	46

since it does not express an intent to be neutral or a reason for being neutral, but merely an obstacle to greater involvement. Almost always, this category was combined with other, positive statements about involvement. In the words of a physical therapist:

> You can't get too involved. There are too many.

Some patients do realize that there is a relationship between time and involvement and this fact is extremely important, as we shall see when we present the recommendations derived from the whole of this material on involvement. This patient illustrates such awareness:

> They're trying to do the best they can, they have so many patients...but they try.

One patient even went so far as to state that, under the conditions which exist with respect to patient load, it is desirable not to give too much emphasis to peripheral matters lest this lead to neglect of the more important medical problems.

> They give you the attention you need. Their job is to see you through sickness, not with your general problems. If so, the real reason for which you came would not be given attention.

The patient just quoted was not typical; she had, herself, been employed in a hospital (in a non-professional capacity). But even this patient was still very much in favor of warmth as opposed to emotional neutrality. Furthermore, she explains that she is less in need of a close relationship with professionals than other patients:

> Maybe because... I don't face the problems that other patients do. I don't feel by any means neglected or left out or unwanted... I have a family, I have my husband and children and relatives... Some have to go through it alone.. (that's) harder... (they are) so forgotten - so left out of everything...if you don't have someone near you

> to talk to you and tell you a word of
> comfort it's hard...[*]

The Case for Emotional Neutrality

1. Objectivity for client's benefit

One of the chief reasons for advocating emotional neutrality was a feeling, on the part of professionals, that distance or detachment means objectivity, and that this objectivity is for the patient's long-run benefit. Involvement, in this view, is equated to "identification" with the patient and is seen as harmful.

Involvement, for example, is said by a professional to "cloud the issues of diagnosis and prognosis." The inference is that the uninvolved professional can do a better job of defining present reality for the patient (diagnosis), and also of predicting what the patient can expect or hope for in the future (prognosis).[**]

Professionals believe that the view from the inside of the situation is too narrow to permit profitable decision-making. A social worker claims:

> You are able to see the good and bad sides

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[*] It is true that there are individual differences in patient need for involvement. While it is not feasible, at this time, to correlate demand for involvement with other characteristics of patients, it was instructive to look at characteristics of those who brought up this topic spontaneously as a problem. Those who had been rejected by their own families or who had been separated from them, (e.g. a widow with son serving in the army overseas), stood out as having potent needs in this respect.

The suggestion that loneliness may make the matter of involvement a potent topic of concern, has consequences for the theoretical structure which we will ultimately have to build. There are connections between involvement and a separate cluster of problems - those centering about topics of boredom and loneliness. Boredom and loneliness, considered conceptually, are quite different. But, for the present purpose, their common element is most relevant, namely, that there is a void, and something is needed to fill the gap. The patient may attempt to fill this gap with a meaningful and not just a formal relationship with the professional.

[**] See Chapter III, Hope and Reality.

> of his thinking, whether it's realistic or unrealistic, what's best for him. This means that you do have to remain somewhat detached ...If you feel like the individual you've lost your own interpretation...and you become the client... It's a broader view than just the individual's own emotional feelings... Maintain objectivity to help them make a decision that is more profitable for them.

Being an outsider has advantages in that the "expert", taking a detached view, can best perceive long-run goals and the means needed to achieve them. If they identify with the patient they may be swayed by his concern with immediate needs, such as a desire to terminate the discomfort of therapeutic exercises. As a physical therapist said:

> You can't let your feelings get too involved in what you're doing... To be more effective, I have to have goals that I want to do and disregard how a person would feel at the moment.

One might ask whether this attitude might not lead to the patient's feeling that the professional is more concerned about some abstract goals or cook-book rules than he is about _me_, the individual.

2. Neutrality and control

Closely related to this category, but with a slightly different emphasis, is the next category, "neutrality leads to better control." In this view, also, the professional is seen to be the more objective of the two partners. And since he is better able to appreciate the importance of long-term goals, he should take the lead in making decisions. This new element is added: distance lends authoritativeness to the words of the "expert", while friendliness may imperil control.

The medical student whom we quoted in the introduction to this chapter as saying, "We're not here to be friends particularly," had also said:

> I think it's necessary to maintain a firm line of I'm the doctor and you're the patient... I think it's very necessary for the physician to maintain control of the situation--to guide it and direct it.

Another medical student said something similar:

> He has got to maintain a distance, so when he must give an order to a patient to do something, they must obey it for their own good...so you must be more of an authoritarian type of person.

With this category, we see for the first time a distinction between professional and student. Students, who are still in the process of learning their roles, sometimes seem to fear that their concern for their patients might lead them to forget what their proper role should be. A student O.T. describes her conflict in this situation:

> Empathy is a good thing, but sometimes I tend to carry it too far. You've got to know when to stop. You know there's a point where you've just got to tell a person you've got to get to work whether it hurts or not. But sometimes I'm a little soft. They called me a softy for a while. I would be right with the patient. But you realize you can't do that after a while... Remember you're the therapist... and you know what's good for them and stick to it... The more personally involved you get, the less therapeutic you are... But I can't stand treating a person like a patient. He's got to be a person.

The established professionals, as opposed to students, were less worried about their positions of authority and their ability to secure compliance with what they prescribe to patients. The one professional who used this category did so as a warning to students against getting in the clutches of a manipulative client.

This whole question of where authority should be vested, and who should make decisions is a separate critical situation which we shall consider again in another chapter. We have touched upon it here only as it relates to involvement.

3. Objectivity as a protection for the professional

There is a final "pro-neutrality" category which merits serious consideration. Professionals are not only concerned about the effect of involvement upon patients. They are also concerned, and legitimately so, about the effect on themselves. The word "objectivity" is sometimes used in connection with this category too, but here the need for objectivity is seen as for the psychic protection of the professional.

When King, in "Perceptions of Illness and Medical Practice" (5), mentions that "emotional neutrality" is one of the chief values in hospitals (second only to the value of life), one assumes that it is, at least partly, because of the fact that in general hospitals death is not infrequent. It is too great a stress to be subjected to bereavement many times in the course of a single year. When attachments to patients are strong, then the loss felt by the medical professional may approach that which he would feel at the loss of a relative or friend.

In a rehabilitation hospital, death of a patient is unusual, but there are similarities in that for much of the time the professional is in close contact with persons who are in situations of distress or suffering. As a professional said:

> It's easy to feel with all and then break down. It calls on a lot from the professional.

The difficulty is magnified if one accepts the old definitions of sympathy which require that the donor of sympathy feel like the recipient.* The professionals cautioned against feeling "like" instead of "with" a patient, and against too great a degree of involvement. Some also said that "you don't want to become involved with the hopeless".**

The persons who exhibited most conflict because of the protection offered by neutrality were nursing home nurses.* One said:

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*See Dembo, Leviton and Wright, (3), for a critique of these conceptualizations, and the suggestion that it is congruence rather than identity of feeling which is required. Congruence permits the donor to lead the recipient out of the distress area while still giving ample respect to the reasons for distress. Also pertinent to the present topic is the exposition of the idea that the essence of the sympathy relationship is the readiness on the part of the donor to give primacy to the needs of the recipient.

**See Chapter V, on the "elite" versus the "hopeless" patient.

> After a few months...you feel, Well I am aware of their need and I can't join the throng that is deserting them too. And yet you find the emotional stress when you have your own life outside, and the frustration of there not seeming to be any answers, too much for you. I feel that I have to get away from it. I cannot make it a part of my life indefinitely because of the demands on my own morale; the depression that it would inject into my own life, this unanswered despair would be quite beyond me. You become emotionally attached to these people, and yet you can't go any place with them.

Another said:

> My work disturbs me a great deal... It's very depressing, and I have had to build up a tremendous amount of resistance to the encroachments upon my personality from these people. I have a feeling as if they want to drain your life force, your energy... And if you are around them you almost - I feel like I am going to disintegrate... Well, I know I have to have my strength to take care of my family...

This was not a category which patients tended to use except in an incidental fashion, or with some confusion of the meanings of involvement. For example, this woman had just been complaining of one professional she described as "quick-tongued" and discourteous and then said:

> This is not a job for anybody that's soft-

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*These two excerpts were not included in the tabulations. They were from records of professionals employed outside of the setting at which the study was done. They were there attending a three-week course in rehabilitation. The purpose of these additional interviews was to get an indication of how the scope of problems seen might be broadened by going outside of the one institution.

> hearted. Maybe you have to be like that.
> I don't know.

We say "confusion", because the kind of hardening of soft-hearts that may be necessary for psychic protection should not lead to discourtesy. Discourtesy or callousness, as well as uncontrolled involvement, may be an indication that the professional should leave this field or get help themselves. A psychiatrist was commenting on the statements of the nursing home nurses:

> What that person needs is to get out of the nursing home business for a while, and go some place for a period of training, and then come back. The ideal situation would be to become emotionally involved under control... Under no circumstances should the patient be identified with. Empathized with, yes. I think every competent member of our staff knows how he would like to be treated if he were in the patient's shoes. But nobody should become lost in the identity of the patient... Some become very disturbed because the patients' pathology happens to strike a very resonant chord in their own personality, in their own fears, in their own family background. It strikes too close to home. When we see staff become identified with the patient we should help them recognize what they have done, not being judgmental about it but indicating that it does happen...and they have to learn that maybe there are certain patients they cannot deal with (e.g. male stroke patients just the same age as their father was when he had a stroke)... I would speak out directly against coldness or detachment... If they become callous or disinterested or fed up, then it's time for them to leave this job...they've had it and they're burned out and they should leave...not out of guilt or shame but recognizing that it is quite part of the occupational hazards of working with this sort of patient. It just gets to be too much after a while.

He indicated, in subsequent discussion, that psychotherapy can be valuable for such professionals. Learning about themselves can increase their competency in dealing with patients who arouse anxiety and hostility. His idea of "involvement under control" is one to which we will return in the section on recommendations.

4. Other reasons given for neutrality

Before leaving this survey of the case for neutrality, we should note that there were other reasons occasionally given. For example, a few individuals talked about why it was better for professionals not to "date" patients. Since this would not be a professional relationship, these reasons do not belong to the theoretical structure we are concerned with.

Two professionals mentioned the fact that involvement may lead to the patient imparting certain confidences, which puts the professional in dilemma. He can neither handle the problem himself nor betray the confidence. It might be something which is so serious a matter, (even involving violation of the law), that he can square neither solution with his conscience. This matter of handling confidences is a separate critical situation which might be investigated later.

Current Teaching Regarding Involvement and Emotional Neutrality

It will be remembered that one of our purposes in this study was to inquire whether current teaching helps to diminish conflict regarding critical situations. One statement which may be made is that the teaching in various training institutions is not consistent. Students from one school of nursing said the following:

> Many of your old-time nurses were taught that, (not to get involved). They were more procedure-oriented than they were anything else. I really think it's getting obsolete now... In our freshman year they tried to stress it with us but I haven't heard that so much any more.
>
> They're not telling us that any more. They haven't since I started training... You find instructors from an older type school still go by this. But your newer instructors... realize this is totally impractical.

Another, who is also currently in training but at a different institution, said:

> Well first of all they don't want you to become attached to the patient. It's hard, I find, if you work with a patient for a long time not to become attached because

> we're human beings. You can't work with someone without this...

Some professionals feel that what they were taught was unclear, or incorrect. And they reject the teaching:

> The favorite theme in school that our instructors used to throw at us would be "personally impersonal", which is such garbage, because I'm not sure just what that means.
>
> We are warned about some things - about being too involved with people. I think that's kind of silly... I don't see how you can communicate with a person unless you do become somewhat involved.

But others are still troubled and in conflict, as witness the O.T. student quoted earlier, who was called a "softy" for yielding to her inclination to "be right with the patient". Conflict is clearly indicated when she states that: "the more personally involved you get, the less therapeutic you are," and immediately afterward: "But I can't stand treating a person like a patient. He's got to be a person."

Preliminary Recommendations*

There are professionals, and also patients, who feel that it is possible to combine the benefits of objectivity with giving the patient the emotional support he needs and wants. But too often involvement and objectivity are seen as points on a continuum, and what is desirable is considered to be a matter of degree. They say that one should:

> "Be involved but not over-involved"
>
> "Not be so involved that you won't make a sensible decision"
>
> "Avoid deep involvement or you will get depressed".

But then the professional is faced with the problem of "where to draw the line".

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*See Chapter I regarding the tentative nature of the recommendations arrived at in the course of the pilot study.

There is another difficulty with the "quantitative" approach: it somehow implies that everyone has a limited capacity for warmth or compassion, that it can be used up, and that therefore one must restrict its use. Here is another instance in which professionals and students differ, though the tables do not reflect it: only students made statements which suggested that compassion should be reserved just for the dying; or that emotional support is needed only if there is no family, and that otherwise "I am for the least amount of emotional involvement with a patient that is possible."

It is the contention of the investigator that there will be less misunderstanding among trainees if, in teaching, the qualitatively different meanings of involvement are stressed. Objectivity is not the other end of the same continuum which embraces warmth and friendliness and knowledge of your patient; the opposite of warmth is coldness and aloofness with all their negative consequences.

The following excerpts from professional records:

> "Be objective but feel attachment"
>
> "If you can become close without identifying"

convey a feeling of qualitative difference and are less likely to mislead than any statement implying that there is an optimal quantity of involvement. This patient also feels that the qualitatively different things - guidance for the patient's benefit and warmth - can exist side by side:

> A therapist tried to be sweet and butter them, but nothing came of it, so she had to make them do it. It's effective... I believe it's like a sergeant in the army. You have to be stern but you have to be friendly, too, and let a person know you have a sense of feeling.

In the psychiatrist's statement, given earlier, the idea of "involvement under control" is a useful one, which appears again in this statement of a student in social service:

> You have to be objective but that doesn't mean that you are so unemotional and so cold that you do not respond to your client... Show them you care, and yet, at the same time...it's a controlled thing, not so overly controlled that you cease

> to be a human being. With some clients you hit it off in such a way that there is something about them that really draws you to them... You've got to realize that you are not their daughter, you are not their mother and you *cannot* give them exactly the same thing. All you can do is be an understanding person, warm and giving, yet...still maintain your role.

"Controlled involvement" is not the same as "under-involvement." It has little to do with degree or quantity. One can meet all legitimate requests of patients for friendliness and assurance of worth, one can know him as an individual and express concern about his difficulties, without, *to any degree*, trying to play the role of daughter or mother, lover or confidante.

Our first recommendation, then, would be to make known to students the scope of meanings that involvement encompasses, and to stress the fact that they are qualitatively different.

A second recommendation to professionals may also serve to prevent or reduce conflict: *in the time when you are with the client, give primacy to his needs*. That part of the injunction which specifies that this should be the attitude *within the time allotted* to the patient, takes into account the *practical limitations* to involvement.* This will also, to some extent, take care of some professionals' fear of "going overboard."

A patient put this clearly when he said:

> It shouldn't affect their lives outside of the hospital, but while they're here it should affect them to the degree where they might want to do something to help. But it shouldn't affect their personal lives.

By giving precedence to the client's needs when he is with you, you avoid giving him the impression that it is all just routine. Yet you don't take his problems home with you and let them affect your personal life - which was the point of the argument for neutrality as a protection for the professional.

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*Korsch (6) reports that the amount of time spent by pediatricians with mothers visiting a clinic with their children, was not correlated with client satisfaction. What was important was how the time was used, and whether the doctor seemed to understand what was troubling the parent.

A third recommendation concerns the kind of needs which should be given primacy - the immediate needs of the patient or his long-term needs. Of course, long-range rehabilitation goals must be kept in mind by the professional when the patient loses sight of them. But *recognition* of immediate needs is necessary in order that patients shall feel that the professional is concerned about *him* and not merely some abstract goals. The main point of the "objectivity" argument was that more weight should be given to the future than to the momentary discomfort that therapeutic measures may produce. The professional can show concern about the discomfort while pointing out to the patient the necessity for sticking to the regimen. He can show that his insistence on working, in spite of the discomfort, is itself a manifestation of caring. And an occasional relaxation of strenuous efforts may be beneficial.

What we have just said about acquainting patients with the professionals' reasons for what they do, is an additional recommendation. Although no patients actually advocated emotional neutrality, we have seen that there are differences among patients in their understanding of the professional position. We have quoted patients who understood the time limitations. Others showed that they were aware that a professional may sometimes have to be "stern like a sergeant in the army", and that he cannot let his involvement with a patient affect his life outside of the hospital. With such patients difficulties in relationship with professionals are not likely to arise over this issue. This information can be given to patients in an orientation period, and for some it will have to be repeated at intervals. For it is a two-way street - patients have to be acquainted with the viewpoint of the professionals just as professionals need to know the viewpoint of patients.

A final recommendation is necessary to take account of the fact that, even when all misunderstandings are cleared up, there will continue to be professionals who will advocate distance rather than involvement. This is likely to be true of those whose values or ideologies are strongly oriented toward control and the leadership role of the more expert of the partners. Such individuals do not take their duties and responsibilities as members of the helping profession less seriously, but they have a different conception of what these duties and responsibilities are. They believe it is easier to impose their ideas of what will be helpful, and to disregard opposition, if friendly relationships do not obscure their authoritativeness. Such professionals must be especially careful about *tactful* behavior, since there is a good chance that distance will intensify the pain associated with recognition of devaluation. It is all too easy for the emphasis on status as an expert, and therefore a more important human being in this respect, to become confused in the mind of the client with status in general. And he feels that he is already devaluated as a less worthy member of society because he is handicapped. As an example of tactful behavior, such a professional should probably not use first names to adult clients. If it is not an expression of friendliness, it can be taken as an indication of lack of respect. In our society we do not use first names to those we keep at a distance except when they are considered to be of lower status.

Summary

It will benefit a student in training for one of the helping professions, those who are interested in rehabilitation, and others to whom client-professional relationships are important, to clearly understand the meanings which the word "involvement" can have. There are two quite distinct aspects of involvement which largely account for whether it is seen as positive or negative. They may be designated as "warmth" and "non-objectivity."

In describing the professional who is "involved", in the positive sense, patients and professionals use these words: friendliness, cordiality, caring, concern, interest in you as an individual, knowing you as a person. Sometimes the idea is expressed in a negative form: not cold or callous, matter-of-fact, routine, business-like, or just doing a job. In the extreme form, lack of involvement is seen as "treating you like a thing instead of a person." The presumed consequences of the positive type of involvement are emotional satisfaction of the client, better communication between professional and client, and increased motivation.

The non-objectivity aspect was a concern only of professionals. Identification with the patient, feeling "like" instead of "with," failure to maintain one's role, were some of the terms employed to describe this undesirable kind of involvement. The most frequent usage was one implying quantity: becoming so attached that one loses objectivity. Objectivity was seen as desirable for two main reasons. The first is for the benefit of the patient - the professional can see alternatives which the emotionally involved patient might neglect. The second is for the benefit of the professional - he needs objectivity to guard himself against certain consequences (for example, depression) which are presumed to follow from being constantly in a situation characterized by distress or suffering of persons to whom he feels attached.

It is suggested that warmth and objectivity are not incompatible. Some recommendations were given which are intended to lessen the difficulties in professional-client relationships. They indicate that, as regards the critical situation of whether a professional should become personally involved with a client or instead attempt to maintain emotional neutrality, the investigator chooses the involvement side of the issue. It may be controlled involvement, (so that the benefits of objectivity may be realized). It may be limited, (by available time). But it is still involvement, not emotional neutrality which is the favored alternative.

CHAPTER III

Hope and Reality

In giving information to a patient about his present condition and about what he can expect in the way of return of function, the critical situation which faces the professional is whether to emphasize realistic appraisal or instead to foster a hopeful outlook. The patient has a point of view about this, and he also is faced with a decision - whether to accept a negative prognosis when it is given, or to cling to hopes in spite of what he may be told. Although most of what we shall have to say will be directed to the first of these problems, the second is inextricably interwoven with, and will help our understanding of, the first.

This critical situation was known before the study began. It is implicit in the caution, given by Michal-Smith (10) to rehabilitation workers, about handling patients' defenses. (For example, they are told not to "batter down" denial.) Dembo (2) has explicitly addressed herself to the problem of hope versus reality. She notes that the position of the professional leads him to stress what the probable outcome will be. On the other hand, a parent of a severely handicapped child emphasizes what is possible - that his child may be the one in a thousand who is the exception.

The present study focuses on the qualitatively different meanings which the terms "hope" and "reality" encompass, and how these meanings influence the choices of patients and professionals regarding which alternative to pursue. It also is an attempt to restructure the apparent dichotomy so that the positive aspects in each alternative can be utilized.

Over-all Preference for the Hopeful or Realistic Approach

Table VI shows the subjects' over-all preference for the hopeful or the realistic approach in dealing with the question of giving information to a patient about his condition or prospects. It was found necessary to include a third category to account for those cases in which it was impossible to detect a clear preference, either because of ambivalence about this matter, or because continued probing led to specification of conditions under which sometimes one and sometimes the other course was preferable. As the table shows, the difference in preference is not a simple matter of position, being a patient or a professional, though it suggests that the tendency of patients is to prefer a hopeful approach and that those who stress reality are

Table VI

Number of subjects who indicated over-all preference for the "realistic" or the "hopeful" approach in dealing with the question of giving information to a patient about his condition and prospects, and the number whose preference is unclear.

Subject-Class	Hope Stressed or Preferred	Reality Stressed or Preferred	Preference Unclear	Total
Clients	11	4	4	19
Professionals	6	9	4	19
Students	4	10	6	20
Total Subjects	21	23	14	58*

*One professional was not specifically asked about the topic; one client rejected several opportunities offered to talk about it.

apt to be professionals or students.* The qualitative analysis will show much more than this, for no patient really had a negative evaluation of hope, except for a particular kind, "false hopes", which we shall discuss at length later. Some professionals have a decidedly negative attitude toward patients' hopes. These advocate "being blunt" or "getting tough" with patients when it is "necessary to make them more realistic". Others are aware of the patient's need for hope and of the possible pitfalls in a realistic approach. Much of their concern, therefore, was about how to "break the news" and how to change hopes to those which are more realizable.

Three different approaches by patients to the issue of hope and reality are illustrated below. They will be particularly important for conceptualization, and so they are discussed at length.

A woman patient (diagnosis - quadriparesis, Guillain-Barré syndrome) fears despair (loss of hope) so much that she does not even want information about her present condition, let alone any prediction about the future. Since any information she receives about the present may imply something about the future, she goes out of her way to avoid information and recommends the same course to others:

> ... You can go around (on ward round days)... and you find them very depressed... They all hate Tuesdays, because they said "Well, I find out I've got something more wrong with me than I ever knew I had wrong." And I told her the best thing to do is just to get out of the room and go down the hall and get out of sight so that you don't hear them. Maybe they think it's a good idea for you to know every detail but I don't think it's necessary.

She is willing to postpone facing reality until it is no longer possible to avoid it:

> ... The world lives on hope. You can always have the hope for the better... Well, until the day finally comes, maybe, that you're not

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*We would again refer the reader to Chapter I regarding the numbers given in the tables. They are important only insofar as they suggest hypotheses to be tested.

> going to be any better. Then you realize what you've got to endure.

Already, we are given a number of threads which must eventually be disentangled. How are "postponement" and "hope" related? When knowledge appears to be too dangerous, is postponing the acquisition of knowledge the only way to maintain hope? Is this typical of someone whose condition is both serious and little understood?

The answers to the last two questions would seem to be in the negative, for the next patient quoted is in somewhat the same situation. His diagnosis was for a long time uncertain; then it was tentatively judged to be multiple sclerosis. He favored full and complete information about present status and prospects:

> I want to know as much about it (as possible) so that I can see how much to expect out of it and what's the average on it and what it really does to you later...

He admits, however, that he will not give up hope no matter what he is told:

> If you were the doctor and told me, "Well, you aren't going to walk, but we'll try to see what we can do for you," I'm going to try to make a liar out of you. Really. Just to see if I could do what you said I couldn't do.

Other instances of this sort are often accompanied by strong expressions of religious faith.

The third illustration comes from a man who is a diabetic and had had a leg amputated. When asked merely about the desirability of information he answered:

> Well, it's important to know the facts. I mean the whole detail is best... It's got to be known how far they can go themselves or what they cannot do.

Further questioning elicited the following:

> I think they should try to stress the hopeful side. If you don't, a person becomes doubtful to himself and then he starts getting self-pity... If I say, "Well, I'm disabled now."

> I wonder, wonder, wonder (long pause) and that doesn't work...

And when asked whether there was any conflict between the two statements, he answered:

> Well, a person can be realistic about where they stand; but still - for the future... they still have to have that hope that they're going to get back... I have that hope. I want that.

We are now in a position to begin to describe the concept of hope. Hope seems to be a way of structuring the future. The future can be characterized by a positive or a negative sign. Hope means that the future is seen as in some way positive. (The various ways will be subsequently considered.) Realistic information *might* mean that this sign would be changed to the negative. Patients want to protect themselves against any change for the worse; and the three excerpts given above illustrate three ways in which protection is obtained:

1. By avoidance of information or postponement of knowledge.
2. By being so secure in one's hopes that *whatever* one is told, the positive sign will not be changed.
3. By cautioning the professional against changing the sign (i.e. give me realistic information about the present but don't rob me of hope for the future).

It will become increasingly clear, as we examine the various reasons adduced for and against hope and reality, that "making the patient more realistic" has two meanings, and that how this is evaluated will depend upon which meaning is intended. If it means changing the sign this will usually be resisted. If it means structurization - giving information which will clarify what it is that a patient has to work with and what are the means which will help him to compensate for what is lacking - then this is usually accepted.

The Case for Hope

The reasons given by subjects for positive evaluation of hope, and the reasons for sparing the patient by not giving him full information, are summarized in Table VII. Later it will be necessary to separate these two questions, but there was so much overlapping in reasons given that for the present purpose, they are treated together.

Table VII

Reasons for positive evaluation of hope, or for avoiding full information regarding patient's condition and expected return of function.

Category	Number of subjects using a given category			
	Client	Professional	Student	Total
1. General statements about the comfort of hope and painfulness of reality	9	2	7	18
2. Emotional consequences of loss of hope; leads to depression, withdrawal, self-pity	5	4	9	18
3. Consequences for motivation and rehabilitation progress	4	6	5	15
4. Imperfect knowledge of reality; "don't know what functions will return for sure"	4	12	6	22
5. Client will not accept negative prognosis	0	7	1	8
Total reasons for hope	22	31	28	81*

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*This exceeds the total number of subjects since a subject may give more than one reason.

1. The comfort of hope and painfulness of reality

The first category includes general, more or less unanalyzed, reactions to the suffering aspect of the client position. Thus a patient who was asked about her expectations of improvement answered simply:

> Oh, it has to be - it just has to be.

Statements that simply indicated patients' need for hope or that hope is comforting were included, also statements about the painfulness of reality:

> You're all emotionally worked up and they
> tell you something--it may be a little
> more shock to you.

The great frequency of client responses in this category may be a reflection of their immediate awareness of the painfulness of reality. But students also use this category:

> (Reality) it's pretty painful sometimes...
> it can be overwhelming.

The relative absence of professional responses of this sort might be explained by the fact that this is a very general category and their answers tended to be more analytical. Their awareness of the patients' need for hope and the painfulness of reality is implicit or embedded in some other category.

2. Emotional consequences of loss of hope

The second category of reasons is similar to the first. The distinction between them is that the second category includes a causal element. Some emotional consequences of loss of hope are enumerated. Not only is absence of hope painful but it leads to depression, passivity, etc. The excerpt quoted on page 34 belongs to this category. Failure to stress the hopeful side, the patient feels, will lead to doubt and self-pity. A social service student who spontaneously brought up this topic stated:

> You can't face them too directly with it, or
> you'll get complete withdrawal.

When the situation is badly mishandled by a professional, the consequences are especially severe. In the words of a psychiatrist:

> The cruel approach - you throw it at the

> patient again and again until you pound the defenses down, taking whatever consequences evolve - it could be suicide, it could be psychosis.

3. Hope and motivation

The third category emphasizes the effect of hope upon motivation and hence upon rehabilitation progress. There are no important differences in frequency of use of this category by professionals and clients. But the differences in emotional tone were striking. A professional had been stressing reality, and only when asked whether there was anything positive about hope, did he give this response:

> The first thought I had was hope as a motivating device and as a maintenance device. I maintain my interest in participating in physical therapy because I have hope of getting return.

Compare this dispassionate appraisal with what a paraplegic patient says about hope and motivation:

> They might get some discouraging information... They may give up. They may be reluctant to try real hard... But I myself, if I were confronted,...I would still exhaust every effort I knew how because I believe in miracles... Push forward...never become submissive...never give up, regardless of whether you become successful or not... Just keep trying. Even the effort of trying is a consolation to the individual.

4. Imperfect knowledge of reality

The fourth category, "imperfect knowledge", requires some preliminary discussion. Knowledge, in the broadest sense, is what this chapter is all about. In everyday usage "knowledge" is taken as almost equivalent to "reality". And when our professional subjects say "one must define reality for this particular patient", they mean that one must impart to him the information or knowledge he needs in his particular situation. When the patient requests more information, it is a request for the knowledge about his condition which, he believes, the professional can impart or withhold at his discretion.

But knowledge used in a less general sense, implies that there is a continuum with respect to knowledgeability, and that even the expert is not omniscient. The return of neurological function is not entirely predictable. New "cures", new miracle drugs, are constantly being discovered. There are advantages to the fact that human knowledge has limits. It gives the possibility of just that minimum of hope which may be absolutely necessary for protection. As this arthritic woman phrased it:

> The doctors know just so much, and that's all. Lots of times when you don't think there's a cure, all of a sudden the whole matter is solved, and you don't know how or by whom, but it is solved. So I don't believe in giving up hope at any time regardless of how serious...just hope and pray that something can be done.

This, too, is what the subject meant who said that, if you tell me I'm not going to walk again, "I'm going to try to make a liar out of you". It is a recognition of the limited knowledge of even the best professionals.

When professionals use this category, it is often in a very different context. To one professional, this means that she can be hopeful without violating her respect for the value of "truth".

> Especially in neurological cases you can be quite truthful and still not cut off any means of hope, because really it's not that clear-cut.

Another emphasizes that this is a reason for extra caution when the professional who is not a specialist is tempted to make predictions:

> There are approximately a quarter of a million spinal cord patients in the United States and there are approximately the same number of physicians... Which means thatmany physicians see very few if any of these patients and... don't know too much about paraplegia or quadriplegia... So they pass the buck as it were, and I can understand their doing this. I would prefer they do this than to make pronouncements to patients which are inaccurate.

5. Client will not accept negative prognosis

The last category was used exclusively by professionals. It suggests that patients tend not to accept negative prognoses anyway, so what is the use of giving them? (At least in the form of direct confrontations.) They will have all of the ill effects described before, and will not be effective in producing the results desired.

Although the patients in this study did not use this category, much of what they said in other connections leads one to feel that there is a basis for the belief of the professionals that "they don't want to really believe that things are as they are". In the words of a physiatrist:

> It has been my experience in dealing with disabled people, now for close to ten years I suppose, that pronouncements by anybody, physicians or other professional persons, in regard to what the patient might expect in his future, are not a very effective way of getting people to understand realistically what may occur. One can do this. There is no question about it. One can sit down and say to the patient, "Now you can expect thus and so to happen.: And perhaps some of them will believe all of it, and some of them will believe some of it, and some of them will believe none of it. Whatever it does do, it certainly will enhance depression, because...usually we have to say to some extent, that the physical picture, as it exists, probably will not get much better, if it gets better at all... So, I think that this is not the way to approach the problem...

What he believes is the way to approach it, will be considered later under the heading "Manner of Communicating Information."

The Case for Reality

Unlike hope, reality was seldom seen as an end in itself. When positive evaluations are made by patients they are not emotionally-toned, unanalyzed expressions of immediate and potent need for reality. Professionals often begin by saying "we owe the truth to patients". But when asked whether it was truth for its own sake, they denied this and then invoked some other underlying reason. There is, however, a general category which is little more than a statement that knowledge is good.

1. General value of knowledge and reality

Those professionals who otherwise stress a hopeful approach go this far in seeing a positive side to reality:

> It is safer to be based on reality.
>
> You must deal realistically with the facts

Table VIII

Reasons for positive evaluation of reality.

Category-Reasons	Number of subjects using a given category: Clients	Professionals	Students	Total
1. Generally knowledge is better; safer; must know what you can and cannot do	6	4	7	17
2. Reality leads to rehabilitation progress via:				
a. Acceptance of necessary surgical procedures or medication	2	2	1	5
b. Motivation; if waiting for miracle won't try	3	3	3	9
c. Acceptance of disability	2	5	4	11
3. False hopes lead to later depression	4	5	8	17
4. Patient's right to know; a matter of dignity and respect	1	5	1	7
5. A protection of professional credibility	0	3	3	6
6. Reality limits anxiety	1	3	1	5
7. Defense mechanisms protect client sufficiently	0	2	2	4
8. "Practical" considerations:				
a. To prevent waste of resources	0	1	0	1
b. To settle affairs in case of terminal illness	1	2	4	7
Total reasons for reality	20	35	34	89

> at hand and take advantage of what you do have. You can't function in an unrealistic world.

This first category is important because of what is not said. It is compatible with the reasons given in favor of hope, because nothing is said about the future having a negative sign. Reality, in this first category, seems to be equated to structurization of the situation. There is no conflict about giving knowledge which does not hurt.

We can begin now to separate questions concerned with giving information about a patient's present medical status and those which relate to prognosis. Most patients are not like this woman, suffering from rheumatoid arthritis and arterio-sclerotic heart disease, who claims:

> I've never asked...what all those pills are for. I take seven in the morning. I would be inclined to worry if I knew just how much was wrong with me... What I don't know, I figure, don't hurt.

Most patients do ask questions and want answers about medication, about diagnosis, and about what they can and cannot safely do. It is relatively easy to detect those who do not want even this much information, so the occasion of difficulty between professionals and clients should not be too frequent when prognosis is not involved. In the subsequent categories in favor of reality, prognosis, prediction about the future, is an important consideration.

2. Reality and rehabilitation progress

The next three categories are alike in that the giving of information by the professional, or facing reality on the part of the patient, are seen as links in a causal chain and the end result is rehabilitation progress (better health or greater independence).

The intermediate step may be acceptance of necessary surgical procedure or medication. A physician, for example, was discussing an optional surgical procedure that many patients are unwilling to undergo:

> Most people feel that if one waits long enough things will correct themselves. Sometimes the patient, after a period of time, will come to the conclusion that perhaps it is in their best interest to have this diversional surgery. Especially if they have repeated episodes of urinary infection...

In other words, the professional objects to the *passive* kind of hope where the client expects that time alone, or nature, or God, will correct the disability; where the patients "come in with the idea that this is a temporary vacation period from walking". They know that some *active* intervention is a necessary step toward the realization of hopes for improvement.

The same objection to the passive attitude is seen in this next excerpt. Here the intermediate link in the chain is seen to be motivation: A realistic outlook leads to motivation which, in turn, leads to rehabilitation progress. An O.T. student says:

> It's no good not to be aware of the reality factors, because that won't do any good for motivation either. Because then the patient might be the type that's going to sit around and expect all of a sudden for his arm to come back or whatever, without his doing anything - or else either it's going to come back all the way or not at all. And that's no good either. He has to know that whatever is going to happen is going to be (through) him working.

The patients who used these categories did so in a rather vague way which did not preclude hope:

> Give them the information they need...help them to accept whatever there is to be done to them.

Or they might admit, when told of the attitude of professionals, that there might be some other patients to whom this would apply, but not themselves:

> It depends on the individual... They might just lay back and relax and say, "Well, I'm going to walk"...and their chances are much slimmer... Get out and do something about it.

But these instances are qualitatively very different from those of students, who sometimes seem almost intolerant of patients' hopes and who give insufficient weight to the risk involved:

> You have some patients who will reach a standstill on their rehabilitation and will refuse to go any further or try to boost themselves any further as far as independence... because they think they're going to get well or they're going to get this or that, so why should

> I do this. In a sense they're handicapping themselves, and if...he is so unrealistic in waiting for this miracle to come thundering down on his head, you've got to make them more realistic. In some cases the only way you're going to get any place is to tell them, throw them into depression - o.k. - but they've got to pull out of that, they've got to build on it.

An apparent contradiction presents itself when we juxtapose this belief in the motivating force of reality with what was previously said about the motivating force of hope. The ends are the same - motivation and rehabilitation progress - but there is a difference in beliefs about what means will be best to attain them. In one case it was believed that hope maintains interest in therapy, but here it is stated that hope will lead to "waiting for a miracle" and not working sufficiently hard at therapies. The specific conditions, under which one or the other effect will occur, needs further inquiry.

The next category is similar to the last, except that a necessary link in the chain is seen to be a special kind of psychological adjustment to one's disability, "acceptance" of the disability.* A psychologist holds a particular belief or theory about the relationship between denial, or non-acceptance of the disability, and psychological energy:

> Denial and unacceptance indicate unwillingness to accept the reality of the situation. Once the patient has begun to show signs of accepting the reality of his new body image, then he is released, usually, in the psychological energy to participate more fully in rehabilitation. As long as he continues to deny the existence of disability, he is really sapping ego-strength or psychological energy in working overtime trying to repress this or suppress this. And because he is sapping all that energy...he doesn't have any left to deal with anything else - problem solving, participating intensively in the program, and so on. So once this problem of denial is worked through, you will always see progress, most always anyway... And this is why acceptance of the disability in the physical medicine setting is of crucial importance.

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*See Chapter on acceptance of loss in "Adjustment to Misfortune" (3).

Denial is frequently mentioned in the literature as a self-protective device and might, therefore, be added to the list given at the beginning of this chapter. However, there is a question about the meaning of denial. How complete can it be? Is it more than postponement of a consideration of the implications of the disability? Is it different from what we will later discuss - a "charade", where the patient knows and the professional knows he knows, but this is not admitted? Is it different from a clinging to a remnant of hope for the long-run future? For the present, we will not attempt to answer these questions, but simply note that denial is used as an equivalent of not facing reality. It is seen as a hindrance to rehabilitation, while its presumed opposite, acceptance of the disability, is seen as leading to rehabilitation progress.

Our understanding of the relationship between acceptance of loss and the critical situation under consideration, will be furthered by what was said by a patient who was decidedly atypical. He was a paraplegic whose injury had been sustained several years before; and he accounts for many of the pro-reality entries on Table VIII, since he made use of almost every one of the categories. Facing reality to this patient (who we will identify as W.S.) means:

> Accepting things as they are, instead of wishing for them to be what you would like for them to be.

The relationship between acceptance and the question of hope versus reality, was illustrated in the following interchange between Mr. W.S. and another patient during a group therapy session:*

W.S.: A lot of handicapped people look so hard to the fact of becoming normal that they forget about the fact that it's possible you won't. And when they do realize the fact that they can't be normal and they won't restore their health and strength as they were before, they can't accept the fact of being disabled or handicapped...

C.X.: I keep saying I'm going to be just like

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*The other patient was not a subject of the present study; he was also a paraplegic and is designated in the excerpt as C.X. The therapist kindly made this recorded group therapy session available to the investigator.

I was before... My mom used to tell me, where there is a will there is a way.

W.S.: That's right...but it don't mean the way you think of... If you keep looking at it that you're going to be perfect, when the time comes that you have to look at the other side, you can't.

C.X.: If I just say, "Well alright I'm crippled," and I'm going to accept the fact then...I don't do anything to improve myself...

W.S.: It don't mean you can improve to the extent that it would be normal again. Everybody's got a limit.

C.X.: A doctor told me three months ago, "I don't think you will ever walk again," and they never made no preparation or nothing to help me walk. And I got to thinking, "Well I'm not going to lay down there and be crippled all my life. I'm going to walk, or I figure life isn't worth living." (Describes how even before coming to this hospital he taught himself to walk)

W.S.: That goes to show you doctors don't know everything. There are some limitations even to doctors... I don't say to nobody to accept the fact...of saying you won't be able to do this and that, and you've got enough courage to try yourself... I don't care how much will power, how much belief, and how much hope you got, you can't go beyond your limits. You've got a limitation. But sometimes you have to go a little higher and push a little harder to get *to* your limitations...

C.X.: I'm not going to face it (yet) because I feel I can do more.

W.S.: I don't expect you to face it now... You've got to hope that you can do better and you've got good potentials. When you realize that there is no more, then you should be able to realize, to face it and accept it... (Otherwise you) don't appreciate what you have achieved.

This excerpt is particularly valuable because it leads us to a consideration of the specific content of hopes about the future, i.e., what it is that is hoped for. If the hope is for achieving complete return to normality, or "perfection", this is unrealistic for paraplegics. It will interfere with rehabilitation progress since motivation may suffer when, in Mr. W.S.'s words, "you don't appreciate what you have achieved". On the other hand, if the hope is that eventually one will reach his maximum potential, this should facilitate rehabilitation. It should make one "push a little harder to get to your limits". But we should note that even this patient qualifies his pro-reality viewpoint to this extent: the experts are not omniscient about where the exact limits will be, and so postponement in accepting their predictions may be justified.

We shall find it very important for our final recommendations to stress content of hope - is it to progress from bed to wheelchair, or to walking with a cane; is it to be able to brush one's own hair, or to be independent with respect to toileting? Hopes can range from expecting to achieve complete normalcy all the way down, to this very modest hope:

> (Even) if it's not going to heal me completely well... I just keep on hoping...a day of relief from pain is something too. Or a minute. Anytime at all counts when you are...in deep pain almost constantly.

3. False hope and later suffering

With this understanding of the range of content of hope, we are in a better position to understand the meaning of the next category: false hopes are negatively evaluated because of a belief that they will, in the long run, lead to greater suffering. This belief was one of the most widely held by professionals and students:

> To hold out false hopes may then produce a greater let-down.
>
> It's better than for him to build up more hopes and then have them really cut off.

And there are patients who agree:

> I want to know just what I can expect to do or not to do. So I don't hope too much. (subject weeping)... It would be an awful let-down to find out that you had hoped for more than you can possibly get.

The emotional expression accompanying this statement is not surprising. There is distress and conflict when patients are aware that whichever course is followed may be painful. Facing reality is painful, but so is the later discovery that one's hopes were false.

There are specific conditions under which even false hopes should be encouraged, as a psychiatrist explained:

> For a very tenuously integrated person, it may be necessary for him to have a false hope and even to engage in a game where the patient knows...the doctor knows it, but nobody says so. (Like a patient, who only admits she has cancer to the night nurse.) At cock's crow - morning routine, the old charade is picked up again. No mention is made of that which was revealed at three in the morning. So with certain patients here (in the rehabilitation hospital). If they were confronted with the stark reality of the hopelessness of their situation they might give up, they might go to bed, develop bed sores and die. They would develop a profound melancholia because the situation is overwhelming and they cannot manipulate their personal situations toward any agreeable end. Operating on a myth, they might function.

We shall have more to say on the subject of false hopes in the section concerned with recommendations. There we shall see that what one judges to be a false hope will depend upon whether one is speaking of a probable or a possible outcome and whether one is speaking of the immediate or the distant future.

4. False hopes and the dignity of the patient

False hopes have also been mentioned in connection with another category of reasons having to do with the dignity of the patient. Sometimes the hopes which a well-intentioned professional attempts to convey are so patently false that they are taken by the client as an insult to his intelligence. To tell aging patients in nursing homes that "tomorrow it will be better," is an affront to the patient's dignity, according to this nurse:

> (They) are becoming childish but have had an adult experience and it would be part of treating them as adults...to say to them, "Well, you know it is due to the aging process, we will make you as comfortable as we can but we

> obviously cannot make you better". I think they would respect us for it, and they would feel that they were being respected... If you keep saying, "Well, tomorrow it will be better", they get a little of the attitude - why should I believe anything you say, and you're going to be with these people a long time... Basically the people that are old now were raised with a stricter moral code ... The personal dignity (that comes with) somebody treating me as an individual, that feels I am able to accept integrity, and that I still have enough mentality left to realize the situation, would be well worth the risk.

5. Protection of professional credibility

An additional reason on the pro-reality side of the issue is also to be found in the above excerpt, namely, truth is a protection of the credibility of the professional. A student O.T. feels that this is an important consideration:

> I wouldn't like to have somebody come back to me and be terribly mad at me because I told them they'd get something back, and they wouldn't. It's more of a personal defense for me... That goes against the whole profession, too. They won't have faith in anybody.

The medical student quoted below denies that this is his reason for advocating reality. The excerpt is included because we learn something of what is communicated to students by those who are teaching:

> I've seen some doctors who take the approach that the honest policy is best... (one said) that he will not do anything without the complete facts being before the patient regardless of how dreary the future may appear... He feels this saves him the trouble later of having to go through an explanation and having the patient say, "Why didn't you tell me?" ... I think there is a real necessity of good methods of telling a patient, or some sort of good rules on what to do... I would prefer to tell the patient the truth, not for the fact of telling him the truth so that I don't have it on my conscience that I'm not being square with the patient. But rather because I think the sooner one faces reality, quite often the easier it is.

This quotation also illustrates what we said at the beginning of this section, that "truth" was seldom seen by our subjects as a "reason" in and of itself. Though truth is usually considered a fundamental value, the closest any of this group came to invoking this value was the nurse who said that older people were raised with a stricter moral code and want integrity in their dealings with professionals.

6. Reality as a limitation of anxiety

The next two categories were seldom referred to. They are interesting in connection with the belief, used as a reason for a hopeful approach, that patients will not accept negative prognoses. The first of these two categories (Category 6 of Table VIII), suggests that patients may not only accept, but may even *exaggerate* the possibility of a negative outcome. Realistic *information* would then lessen anxiety.

> When they get terribly fearful and maybe expand on the actual facts, we're able to bring the person back to some realistic frame of reference... We put a floor under the anxieties.

Undoubtedly, both types of patient reactions can occur. It should be noted, moreover, that this is another instance in which realistic information is *not* incompatible with hope. On the contrary, the realistic approach, in this instance, is a means of changing the outlook for the future to one which is more *positive*. A physical therapist illustrates this:

> It's having them face what they're up against, as gently as possible. Always giving them these little taps toward reality - toward what is in store for them, toward what they *can* do. They'll say, "I can't walk", not, "I can get around in a wheel-chair and maybe go back and forth to work and still support my family." The cannots just flood their minds before the positive. So your role is to teach them the positive - what they can do.

7. Defense mechanisms protect client sufficiently

The use of category 7 indicates that the subject subscribes to the belief that patients won't accept negative prognoses; but here the belief is used as a reason for a quite different sort of recommendation. Whereas, before it was used as a reason for *not* imposing reality upon a patient ("What's the use of confrontations when they are ineffective?"), here, the same sort of belief, ("He will rationalize anyway"), is used to explain that stressing reality will not hurt:

> I tend to be more on the truthful side because I feel, if a person can't accept it, most of them have enough defense mechanism that they ...rationalize quite well... Either a person will be able to face it, or they rationalize and say they are getting better every day, whether they are worse or not.

It is fortunate that this response is infrequent, for it indicates a lack of caution in dealing with a patient's defenses.

8. "Practical" considerations

The last two categories are described as "practical" considerations in that they deal with how a patient can best handle his economic affairs and spend his time. Only once during the current investigation did we encounter a belief which is frequently heard outside of this setting: that when a condition is actually hopeless, a patient may squander resources, money or time, in a vain search for a cure, unless he is confronted with a decisive statement about the impossibility of improvement.

> I always felt that giving them false hopes... made them much more unhappy...wondering whether they should go to Billings or to Mayo's or run down to Houston... They dissipate their funds. They dissipate their time and energies, their opportunities to be with the ones they care about and to do things that they probably wanted to have done in their life. I think that's a terrible tragedy when they do that to people... She's willing to run all over... and die someplace - God knows where. Whereas if she knows the truth she's going to adjust herself and she's going to manage to make her money last out her lifetime.

This is a complicated matter and should be approached with caution. If it is indeed true that patients are unwilling to accept negative prognoses, aren't they likely to engage in this "running around" anyway, and perhaps even fall into the hands of charlatans who will give them some hope?

The previous reason is by no means limited to cases where a terminal illness is involved. But where there is danger of death, the physician feels a special responsibility to permit the client to set his affairs in order. One professional said:

> The patient should be given the right to make a plan... I think this is something that bothers many patients. It's their personal problems that have been left haphazard.

And another professional gives examples:

> There were certain affairs that she had to straighten out as to who she wanted to leave money to. There were certain people that she hadn't seen, that she wanted to see. And another woman...had three small children. She might want to make some kind of provision for the children.

The only patient who used this category spoke about other people, not himself:

> I would like better not to know it. I don't have nothing to settle. If there are people who have a big estate...then may be they want to know.

A suggestion regarding how to deal with these practical matters is given below. This physician tries to put herself in the position of the insider, and compromises. Instead of giving "unvarnished truth" that will destroy all hope, she takes advantage of the fact that even experts are not omniscient:

> I don't tell people they have cancer, if you're going to ask me that next. I don't do it. In my experience, most people are not able to accept the final diagnosis. I'm not. I know I'm not. I don't want to hear it. And I go on the general principal that I'm a pretty average, normal person, and if I feel that way, most people do. Now men, upstanding, independent, heads of families...have to know, and generally say that they want to know, and I think triple twice about these people. I don't think about other people at all. I just don't give final diagnosis to other people. But that type of person I think a long time about, and I ease up on it, and I compromise by saying, "Yes you did have a malignancy, but we got it all out and you've got just as good a chance as the next guy. But of course, we're not prophets and you have to make your arrangements." That's the way I would do it.

Manner of Communicating Information

In many instances, it was difficult to decide whether the subject, in general, favored a realistic or hopeful approach. Sometimes this was because he stressed, instead of either of these, manner of communicating information about what can be expected in the future. Even when one side or the other of the issue was favored, the question of how it is done was still deemed important. Students often expressed a wish to know "some good rules" about how to "break the news."

The subjects who gave recommendations on this subject emphasized: (1) timing, (2) knowledge of the individual patient, (3) avoidance of "confrontations" and blunt statements, (4) the kind of help that professionals and other patients can give to one in the process of integrating realistic information.

Client subjects stressed the first two of these.* Their references to timing recall what we referred to as the postponement defense:

> (Optimism at first is justified) to get over that first hump.
>
> I would say you would have to evaluate the person's emotional condition...because usually when they come into something like this the change is so great that you're not accustomed to it, and you're all emotionally worked up.

Students also stressed these two kinds of recommendations: timing, which the word "gradually" connotes, and "knowing your patient".

> You have to know a lot about the patient. About his reactions to things... I think he should be told gradually... There are certain times that things should be said; (not) walk in when they are depressed.

A psychiatrist tells why there is a need for caution: to err on the side of going slowly can merely waste time, to err on the other side can be catastrophic:

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*In general the topic of how to communicate information was not a concern of client subjects. There were a total of 6 client statements on this matter as opposed to 26 from professionals and 30 from students.

> You can make a mistake, and with certain patients you may go too cautiously and waste a lot of time. With other patients you might falsely assume that he has a good deal of flexible ego strength to tolerate a blunt confrontation... This may simply be a mask, and you may wonder why the patient has suddenly gone downhill, has become depressed.

A second caution is given by the same informant: "knowing your patient" is something more than just taking at face value his statement that "he can take it":

> You can't accept their point of view because they may be denying to themselves their capacity for severe depressive reaction. Now one is very careful, there are certain individuals who say, "Look tell me, what's going on with me?" And they can handle it. Others who, in their neurotic need to assert their strength, (say) "I need to know all"... And when you do tell them these things, they collapse like a house of cards... Gauge the patient's defenses, ability really to take bad news. And do not be seduced by that kind of "I am brave, doc, and I can take it."... And again it requires intuitive judgment on the part of the physician. Intuition really is a manifestation of a great deal of experience and gaining from mistakes.

Students and professionals, in the hospital which was the setting of the study, are exposed to a philosophy of "avoiding confrontation". At a staff conference, a medical student asked how to give a poor prognosis to a patient, and the answer was:

> The best way is not to approach it. Elsewhere you may have seen a sadistic physician who said, "You've had it", or a dishonestly optimistic one who said, "This will go away in six months". Patients seldom ask directly; they really don't want to confirm what they suspect. If they should, the physician should be as optimistically honest as he can. Emphasize the therapeutic program, not that there will be no return neurologically. Most of what people learn they pick up indirectly. In time one doesn't need to confront anybody.

In our conceptual terms, a structurization of reality will gradually emerge without the necessity for the professional having to intervene and attempt to change the sign which the patient sees as characterizing his future.

A physiatrist described how this comes about:

> I think the environment plays a very important role, and some of the activities that we have here, such as our group psychotherapy program... The therapeutic program itself is a way of determining for the patient what he can expect... He has these temporary splint devices, or he is put on the parallel bars and he is given instruction on how to begin to learn to walk. Isn't this so much a better way for him to learn what his muscles can do than if the doctor sits down and tells him about it?... They learn by all of the things that are going on around them. They learn from their peers who have similar problems, who have not had return of function. They learn from the therapist who gives them instruction. They learn from the doctor in his rounds. Without direct confrontation techniques. It's not what is said, necessarily, that is important. It is what is implied and what is unsaid. And people learn from this too.

Some portions of this process were enlarged upon by a psychologist - for instance the part played by other patients:

> In group psychotherapy...the technique involved is really understanding that a patient will accept statements from another that he will never accept from professional staff... Because he knows that they have gone through the same thing... And I feel more like accepting what they tell me and more comfortable about coming out with my fears about this than I would with some stranger or some guy with a white coat on.

Information Giving and Inter-professional Relationships

While questions concerning inter-professional relationships were outside of the scope of the present study, one question in this area is closely related to the present topic of concern. Professional subjects frequently raised the question, "Who should tell? Who should give the patient the information about his condition and expectations?" And the usual answer was that the doctor should. Or it was stated that whatever information is given to a patient by members of other professions must depend upon what he was told by his doctor:

> You have to really coincide with what the doctor said. I feel you do. You have to be together on this.

One subject stated that the position of the therapist is that of "low man on the totem pole" and, therefore, he should not use his own judgment about whether or not to give information. This is what para-medical personnel are taught. But although they are correct in saying that "it is the doctor's role to tell", it would be incorrect to assume that the question of hope versus reality is not a concern of other professionals.

One student made this insightful statement:

> Some patients will come to an occupational therapist...because they don't really know whether they want an answer. If they really wanted an answer, they would go to the doctor. So they want to be reinforced, or they want to seek it just to feel they have sought. But they don't really want to know the answer, because they are afraid of the answer.

In other words, they give lip-service to the value, "knowledge", but their real need is to protect themselves against change of sign. A psychiatrist commented on this last statement:

> They are protecting their denial of the hopelessness of their situation... "After all, it wasn't the doctor who told me." So they continue to play the charade during the waking hours. At three o'clock in the morning when their defenses are down and they're sleepless with anxiety, when they have developed a close relationship...(as with a) private duty nurse, (then they ask). They get it from the underling whose information they can then disallow."

And, so, willy-nilly, all professionals dealing with the disabled, may be placed in a position where they will have to have some kind of answer for their patients' request for information about their condition and their future. They may be able to evade direct questions about diagnosis and prognosis, but in whatever they say (or fail to say) attitudes are conveyed. The understanding of the above reasons in favor of hope and reality and the cautions here given, will not only help to reduce possible difficulties in the client-professional relationship, they may even avert graver consequences.

Preliminary Recommendations

Some suggestions derived from the analysis of the critical situation of whether to foster a hopeful or a realistic approach to the matter of giving a patient information about his medical condition and prospects, will be pertinent to future investigation as well as to future teaching. The first is that posing the issue simply as hope versus reality is not correct. Some subjects refused to accept the dichotomy:

> But then there is a hope in reality too. You can't pull them apart. In facing reality you get a different sort of hope.

Their refusal helped the investigator to the conclusion, that in dealing with this issue, a great deal of specification is required:

(a) As to content of hopes - e.g. is improvement of ambulation by means of assistive devices meant, or return to "normal"? Much of what our professional subjects said indicated an attempt to change the content of patient's hopes to that which might be realized:

> You give them some goal to work toward... A patient, even from a wheel-chair and with just one arm, can do a lot of things in the kitchen.

(b) As to time-perspective - for the immediate future reality may be stressed because of the tasks just ahead; for the long run, hopes of eventual new discoveries may be encouraged. A social work student was speaking of a child who probably would always need braces:

> He thinks that one of these days he's going to throw those braces out the window and walk all by himself. And for a child, I think it is very hard to say, "No, you're going to be in those things for life, and there's nothing you can do about it". I don't think that kids should have that much hope taken away from them. And who knows, in some of these cases it might be possible with medical discoveries. What he has to face is the "here and now"... His adjustment right now is getting into a special school, using the braces, getting around and not just sitting like a bump on a

> log and doing nothing with his life... The present reality you have to face that. But that doesn't necessarily remove the hope that maybe some day things will be better.

(c) As to whether the hopes are passive, ("waiting for miracles"), or accompanied by active striving to reach the limits imposed by disability.

(d) As to whether expectations about the future are being discussed in terms of probabilities or possibilities. Dembo (2) has asserted that professionals are guided, in their expectations, by probability of outcome and clients by what is possible. The tendency for professionals to stress probable outcome, was seen also in the present study. The interviewer had asked:

> If there were, let's say, a 10% possibility of recovery of function, but 90% of not recovering, would you stress the 90%, or would you stress the 10%?

And the subject answered:

> I think I would probably tend to stress the 90%, mentioning but not really encouraging the 10%. You mention that there is a possibility, that it very seldom happens, that it might happen to you just as it might to any one of a thousand other people, but that you should learn to live with the 90% before you start looking for the 10%.

Patient emphasis on what is merely a possibility is seen in this excerpt:

> I feel that there is a possibility that things could turn out for the better... I felt that I knew a miracle man would pull me through that. This miracle man was God... Everyone must put forth effort to do the things called impossible, and there's the possibility that even the impossible can be done... We used to read about Buck Rogers flying around in rockets in outer space... And this thing that appeared to be impossible is an actual reality now...

Management of a case depends upon the professional gauging probabilities accurately. Also, as we have seen, a professional may feel that his reputation for veracity may suffer if he permits "false hopes" to exist. What the professional must be aware of is, that what is seen as a false hope, in the context of a discussion of probable outcome, may not be false when possibilities are being considered. The professional must also be made more aware of how potent the question of possibility is for the patient.*

With these specifications much of the conflict in the area of hope and reality disappears. It is seen that there is such a thing as realistic hope: hope that *some measure* of improvement is *possible* in the *long-run* with an *active* rehabilitation program. There is no doubt that a patient's motivation and his whole attitude will be materially affected by seeing at least some possibility of significant improvement in the future. And the professional can safely ally himself with the possibilities that the patient sees as existing in the long run. He can take advantage of the fact that no expert is omniscient about future discoveries, and then can stress the fact that an active striving rather than a passive "waiting for miracles" is the best bet for reaching these long-term goals.

Our second set of recommendations consist of endorsements of what our subjects have said about the professional going slowly in approaching the topic of what the prospects for improvement may be.

(a) "Going slowly", in and of itself, will help to avoid one source of difficulty in professional-client relationships. The client is less apt to see the behavior of the professional as insensitive".*

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*A 1931 investigation of "Anger" by Dembo (1), suggested the following hypothesis: The more potent the issue for the person concerned, the less evidence he will require to reach a judgment regarding the possibility of an event occurring.

Another interesting hypothesis is this: The more remote the future that is being weighed, the less is the real evidence on which to base expectations, therefore, the more likely is the shift of focus from probability to possibility.

(b) "Going slowly", will make it more likely that there has been sufficient time for the patient to get "over the first hump". During this time he may find it very difficult to sustain the additional suffering that negative expectations would bring.

(c) Time is required also to "get to know your patient", to gauge how he has met stress before, to learn what those defenses are which we are warned against battering down, to determine whether the situation is such that even false hopes are necessary.

(d) And finally, time is important for the process of restructurization. The best way of changing content of hopes is by the patient's gradually becoming familiar with the rehabilitation program. By learning about the assistive devices which exist, by seeing how other patients with similar disabilities are progressing, by admitting fears to those peers with whom he is at ease, the patient himself, may come to feel that further postponement of accepting the implications of his disability, is not the best mode of adjusting to it. And thus, the professional is not required to confront the client with evidence to make him more realistic.

Summary

In approaching questions centering about hope and reality, clients focus on the immediate painfulness of reality, the painful consequences of loss of hope, and the pain of later discovery that one's hopes were false. Suffering is their chief concern and alleviation of suffering a great need. In the main, their preference is for hope because of the comfort it brings, and because motivation requires seeing some possibility of improvement.

Far more than do patients, professionals see benefits in reality. Some even seem intolerant of patients' hopes, because they believe that hope can lead to "waiting for a miracle" rather than working sufficiently hard at therapies. Other professionals are aware of the risks involved in attempts to change a hopeful outlook.

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*There were few complaints on this score from patients in this rehabilitation hospital setting, perhaps because of the philosophy to which the professionals at this institution have been exposed. But elsewhere the situation may not be the same. During a meeting of the Easter Seal Society in 1965, a parent described indefensible behavior. After the parents had traveled a long distance to get an opinion from a noted specialist, and after a lengthy wait, the child was examined. Then the parents were called in for two minutes. In these two minutes, they were given a name for the condition, told that it was hopeless, and dismissed. (See also Dembo, "Sensitivity of one Person to Another", 2.)

Hope, in general, is seen as attributing a positive sign to expectations about the future. The particular content of hope and the time perspective involved should be specified. It should be made clear whether it is active or passive hope that is meant, and whether possible or probable outcomes are under discussion.

Two meanings of "a realistic approach" are distinguished and designated as "changing the sign" and "structurization". It is the opinion of the investigator that when the patient's view of the future is characterized by a positive sign, he will be adversely affected by attempts to change this to a negative one. Structurization, on the other hand, involves clarification of what a patient has to work with and information about the means available for producing improvement. It encompasses all that information which is most acceptable and least likely to hurt because nothing is explicitly said about a negative outcome.

The injunction to go slowly in approaching the matter of giving information to patients about their medical condition and prospects of improvement, also receives the endorsement of the investigator. Time is necessary to gauge the ability of the patient to handle information, and time often makes confrontation unnecessary.

CHAPTER IV

Independence and Dependence

Independence is a value which professionals and clients share. Not only does our culture, in general, reward independence, but also the particular setting, the rehabilitation hospital, is devoted to the restoration of physical independence. The questions in this area which originated with the subjects were, therefore, not about the relative merits of independence and dependence. Instead, their spontaneous references to the topic were based on the assumption that the advantages of independence are self-evident. For example, this professional began the interview with a discussion of how family attitudes may interfere with achieving independence:

> I've observed that the patient's family can very often interfere with the rehabilitation process. Family attitudes...are very often the antithesis of what we're trying to do here. They coddle the patient and cater to them... We are trying to get the patient to do as much for himself as possible, and on their visits they undo everything we try to do.

Usually, only when the experimenter would pose it as a critical situation and ask whether independence should always be stressed, would the subject qualify, or enumerate conditions under which dependence is permissible, or mention some aspect of dependence which is positive.

There is, then, little use in tabulating over-all preference for one of the two alternatives. All sixty subjects discussed the issue. Of these, only two exhibited a preference for the dependency side of the issue. This was on the overt level. Unacknowledged dependency needs is another story to which we will return. The two subjects who diverged from the pattern were women patients aged 48 and 52. Both had worked outside of the home until they suffered a stroke. One had suffered only a mild stroke and has recovered most functions. She said:

> They wanted me to be more independent, and I was forced to be. Maybe it's good but I don't know. I think that especially in the early stages you have to feel that you have somebody to depend on... I believe in help when it's convenient...but for instance, my husband doesn't. He thinks I overdo it.

The second woman is still considerably incapacitated:

> When the nurses come in the morning and start putting (the brace) on, I don't say, "No, let me do it myself." I'm only too glad to have them do it... I have tried...on weekends... and I usually have to end up with my husband helping me... A woman enjoys having someone wait on her more... I have a daughter...and I think this irritates her a little bit, because I depend so much on my husband; but my husband and I have a very good relationship... I have worked an awful lot since I've been married. And he's always helped me with my housework.

There is good reason to believe, from what professionals say, that a group which is not well represented in our sample, the very old, would also accept a dependent role. This, however, does not give rise to great difficulties in professional-client relationships because their particular needs for dependency are so well realized by the professionals. The following is a very characteristic statement:

> There are a lot of times when you get in somebody that's 88 years old and they've worked so hard all their life and they've had two strokes...and they would like to sit back and let somebody else take care of them. My feeling is that they've earned it. And they really aren't going to get very far anyway. And why not just let them enjoy what they have left of their old age?

These, however, are the exceptions - the very old, and among our subjects, only two patients who acknowledge that, at least in their present circumstances, they want to be dependent.

The opposite point of view, about the value of independence, is expressed by a stroke patient. He had indicated that he only wanted help when it was "absolutely necessary.":

> And this is the reason why I won't go home before I'm 100% sure I can go at least with a stick, but without a chair, and that I can do everything.

And no further reason was seen as necessary to justify independence. When asked about the reason, it was simply:

> The feeling of independence. I was all my life independent - in my business as well as in my way of life.

Similarly, this patient feels that independence needs no further justification:

> It's just good. We all like to be independent... I think it's just a natural state of mind. I think it's very healthy. That's why.

The more articulate professionals are usually more analytical about the reasons, but they, too, give indications of the strength of the value. This professional, for instance, in spite of many qualifications about occasions when dependence is permissible, still felt that:

> Independence is the goal of the human spirit.

The tables which follow, then, should be read with this in mind: there may be specific conditions under which dependence is permitted, or there may be positive aspects about dependence which the experimenter could elicit with additional questioning. But it seems that dependence, per se, is seldom evaluated positively. Since this is so, we can expect that discrepancies between client and professional attitudes will be more subtle than the ones we have encountered in dealing with previous topics.

Reasons for Positive Evaluation of Independence

Table IX summarizes the reasons for positive evaluation of independence.

1. Reasons related to space of free movement

The first cluster of reasons for independence have been grouped under the heading "Space of free movement."* The most obvious fact about disability is that physical goals are less easily accessible. The most obvious fact about rehabilitation is that it is designed to promote increase in the accessibility of these goals - to increase the space of free movement. Increasing the space of free movement of patients has these assets: The sheer convenience of being able to reach desired

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*This term, derived from topological psychology, was found very useful in the context of disability in a previous study reported by Ladieu, Hanfmann and Dembo (9). The present study confirms a number of its findings.

Table IX

Reasons for Positive Evaluation of Independence

Category	Number of subjects using each category.			
	Clients	Professionals	Students	Total
1. Space of free movement:				
a. For convenience; goals become accessible.	4	1	4	9
(Expressions of appreciation by patients for knowledge imparted and assistive devices.)	6	-	-	6
b. Satisfaction of self-determination.	2	3	3	8
c. For security; reduces fear of emergencies; won't always have someone around.	8	5	3	16
Total space of free movement	20	9	10	39
2. Feelings and ego-needs of client:				
a. For morale; feeling of accomplishment, etc.	5	6	10	21
b. For status; dependency is degrading; "reaction formation against feeling no good."	10	9	11	30
c. For privacy (especially in personal hygiene).	2	4	2	8
Total ego-needs	17	19	23	59

Table IX (continued)

Category	Number of subjects using each category.			
	Clients	Professionals	Students	Total
3. Consideration of the larger unit:				
a. Needs of others infringed; burden on the family.	7	7	6	20
b. Consequences of lack of independence for placement; leads to nursing home.	1	7	2	10
c. The demands of society; "getting off the welfare rolls".	1	5	1	7
d. Status and role of bread winner.	3	3	1	7
Total reasons emphasizing larger unit.	12	22	10	44
Total pro-independence reasons	49	50	43	142

goals without having to wait for another; the satisfaction of self-determination - of coming and going as you please; and the security of knowing that one can handle emergencies that may arise.

All of these are primarily matters of agreement rather than of difficulty in professional-client relationships. Indeed the convenience of having physical goals made more accessible is frequently a cause of expressions of gratitude on the part of patients. They appreciate the knowledge which professionals have imparted to them, and the assistive devices they have been acquainted with:

> They're doing their part all around...now I'm progressing and they're teaching me different things... They have some wonderful things...a kind of sticking material and they put that on and it looks like your dress is completely buttoned... When you go along and see how you are doing, then it changes your whole attitude. Because I never thought that I could stand between those bars and walk.

The concept of space of free movement is somewhat broader when particular physical goals are less emphasized than general self-determination: A nurse says:

> Especially for a younger person I think we should strive for as much independence as possible. And to get this person back on the road and out into society where the patient can be their own boss again so to speak, and do for themselves, come and go as they please.

And a social service student:

> Try to help him feel as much in control of his life as possible. If he can be helped to do little things even, for himself - dressing himself, bathing - even for a housewife to learn some cooking she can do, say if she only has one hand that's usable. I think this is a big step for them to get back to a level close to what they were before.

Another aspect of the space of free movement cluster, an important reason for learning to do whatever one can do alone, is anxiety about the prospect that at some time a very important goal may be at stake and there will be no one around to whom the disabled person can turn for help. A professional says:

> The thing you have to recognize here is that the individual isn't always going to be with you. There is no human situation in which you are totally with another person all the time, so that you have to learn to do things on your own.

This "security" aspect of space of free movement is especially potent for a patient who is severely handicapped:

> You have to learn to try to do all you can for yourself... Because there isn't always someone around that can do this for you... There's always certain things that stick in your mind when you're helpless - the fear of fire, the fear of being trapped, and the fear of falling. And if you don't learn to help balance yourself, help yourself through doors, etc., that helps to make the fear worse.

This category seemed to be more emphasized by patients than by professionals. An important consideration here, one to which we will return when we consider the questions of safety and risk, is this: The value losses suffered by the disabled may make them especially sensitive to the possibility of additional losses, and the necessity for protecting those which remain.

This then, is one cluster of meanings which independence has, where the emphasis is on reaching physical goals, and the convenience and security of the patient is stressed. Whether the differences between clients and professionals in frequency of use of these categories are significant has not been determined.* It would seem that even if they are shown to be significant, this need not portend anything about difficulties in professional-client relationships. Nevertheless, there are some clues to possible difficulties to which we must be alert. Further analysis may throw additional light on these matters:

First, heavy stress on independence might, in itself, cause some problems. For example, there was more than one patient who said:

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*See Chapter I for the reasons why determination of significance of differences in the pilot-study data was not judged to be appropriate.

> I don't want to leave here until I'm completely independent.

Unfortunately, in some instances the prospects are not too bright for this occurring. It is possible, then, that when such a patient is discharged without being completely independent, there will be dissatisfaction. The problems involving time of discharge are a separate area which will need investigation.

Secondly, the category "self-determination" is closely connected with the critical situation centering around questions of control and decision-making. The near unanimity which we find in our subjects when independence with respect to physical tasks is focused upon, is lacking when independence in this broader sense is meant. Yet, as Rusk says, "Self-sufficiency cannot be nurtured if it is denied at the outset."*

Third, in discussing these reasons for independence, patients tend to focus on new learning - that is "accomplishing what you came here for," for that enlarges the space of free movement. Professionals, on the other hand, are very concerned about the possibility of regression:

> Unless something is reinforced continually it's very easy to forget.

And thus it was that some professionals felt that even after a particular task has been learned, the patient should still practice at every opportunity. We shall return to this and point out some consequences of this difference in emphasis after considering some of the positive aspects of dependence.

2. Reasons related to feelings and ego-needs of the client

The second cluster of reasons for independence have been grouped together under the heading, "feelings and ego-needs of the client." Certainly, feelings and needs are involved in the first cluster, too, especially when the broader aspects are mentioned, like self-determination or when fears of further value losses are implied, but these are not the primary consideration.

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*Quoted by Eustace (4).

The first two sub-categories under the general heading are not always easy to distinguish. The distinction lies in what separates these two statements: "life is more worthwhile" and "you are a more worthwhile person." The first emphasizes the happiness and morale of the client and the second emphasizes his status and has overtones of devaluation of the dependent.

In the first sub-category we would include such statements as these from professionals:

> It's important to feel that you are independent ... It's good for your ego, it's good for your morale, and it makes you feel marvelous.
>
> He becomes...much less happy or satisfied I would think.

And from a patient:

> Actually they're depriving themselves of the pleasures of living... It's more of a thrill... to know that you have done these things on your own rather than let someone else do them. I feel that you will enjoy them more.

Other statements used in this connection were that independence leads to a "feeling of well-being", "a feeling of accomplishment", "feeling confident and optimistic"; or that it is "gratifying", "one is happy when productive", and "life is more tolerable."

This begins to shade off into the status category when words like "self-esteem", "self-image", and "pride" are used; by the professional:

> Some people need to be independent to support their ego...it certainly helps the person to improve their image.

by a student:

> I think in the long run, when they do achieve certain degrees of independence, they're much more grateful, because they can maintain much more self-esteem and they can maintain their individuality much more.

by a patient:

> It makes me feel prouder of myself if I can do it.

The word "pride" has a strong status component in this quotation from an amputee:

> (I.: What's bad about dependence?)
> S: Well it sort of takes down a little bit on the pride. That's what my definition would be. It touches on pride. Whereas you could before, why, you can't now. I'll give you an example. My wife is working now, see...I want her to stay home. It's my pride. I have to accept it because I understand it's got to be done, and I don't have no grudge against her or anything like that.

Whereas the previous statements were couched in a positive way, in this, the negative and self-devaluative feelings are prepotent, the comparison of pre-illness and post-illness self is emphasized, and there is even a hint (although he disowns it) that it is possible to feel a "grudge" against the one upon whom you are dependent.

Even when a patient exhibits no self-devaluative feelings, he is aware that others may pity him (which connotes devaluation) and so he is eager to demonstrate his independence. As this paraplegic says:

> Most people that are well and not handicapped have a tendency to have pity and sympathy for them... I would do without before I would accept (help) out of sympathy or pity... Somebody comes along and says "can I give you a push", I say "no thanks I can manage, I got two good hands."

Many professionals are well aware of the patient's concern about status and his need to demonstrate independence:

> I think I'd probably expect my patient to get along with less help than I would... Mostly because it's important for them to prove it to themselves as well as to others...

We would not expect overt expressions of devaluation in professionals working in this area, but occasionally they give indication of having such feelings:

> (Accepting help when you don't need it), it would seem like it would be personally degrading, even though the person would try to get away with it.

The student nurse quoted below was speaking in the context of what it means to the patient, but it is by no means clear that she does not share the attitude:

> (I: Now why is it so important that people be independent? What does it mean to the person?)
>
> S: Well, that they're a worth-while person; they can function on their own. They're mature. When you think of somebody that needs help, you think of a baby or somebody that's old and senile. And you say, "Oh that person is gone almost back to childhood." They have to be diapered and fed and everything like that. I think that's kind of an insult for somebody to constantly have to have help. And I think that's one of the functions of rehabilitation, to get them back.

The status aspect and devaluative attitudes are most often encountered in connection with two particular problems. One concerns personal hygiene; the other, the traditional male role as bread-winner. The former is the subject of the next category, the latter will be discussed in connection with the demands of society.

The feelings of shame connected with toileting from childhood on, the cultural requirement of privacy in matters of personal hygiene, lead to special vulnerability when one is not independent in this area. There is a difference, however, in the way that professionals and patients approach this problem. Patients may mention their embarrassment:

> There are a few things that are absolutely necessary that you feel embarrassed that you have to accept help on some of those things. For instance, taking a (dental) plate out of your mouth...I can't get my arms up that high...and using toilet paper...I've tried and tried and I can't do it and I've had to do without.

Or they simply dislike the intrusion of another person. Any handling of the body may be seen as an invasion of privacy. This was the reason for negatively evaluating dependency which was encountered in the record of a paraplegic man:

> To keep from being handled; I really hate to be handled. I don't know, it just irritates me.

Professionals did not stress the desire of the patient for privacy, but rather the status aspect. It was seen as a question of self-respect:

> Independence in personal hygiene and things like that are important for self-respect. It's very hard to feel self-respect when you need somebody else to help you do your toileting or do your washing or dressing. I think that's the sort of thing that people would rather do for themselves most often.

The following professional considers the desire to learn to achieve the goal of self-care in personal hygiene, a criterion of normality:

> When you find one who doesn't seem interested in learning that, I think there's quite a bit wrong with them, more than physically wrong with them.

This is not necessarily a devaluation of those who have not the capacity to achieve this goal. Many, who are not professionals, are not so tolerant. So this ability might determine whether a family will be willing to accept the handicapped member at home or will send him to an institution:

> If a patient can be independent in his personal needs a family who might not otherwise be willing...will then be able to take them home... They can be around, then, without being such a tremendous burden on their family that they're not longer welcome.

We shall return to the question of "being a burden". At this point we only wish to point out that there is a special quality about dealing with the bodily functions of an adult that is different from the matter-of-fact way we approach the same functions in an infant. And it is different from the way other "burdens", like transferring or feeding, are approached - that is, in terms of energy required or time consumed.

With respect to this cluster of reasons for the evaluation of independence, then, we can conclude that patients and professionals agree that independence is important for what it means to the morale of the patient - he's happier when he is productive; that dependence may lead to feelings of self-devaluation or to devaluation by others; and that it is especially important to be independent in matters of personal hygiene where privacy is desired. In spite of the similarities in viewpoints about these reasons for the desirability of independence, difficulties in the relationship between professional and client still may arise. The professional must be careful not to betray any sign of devaluation of the dependent. The patient is well aware that devaluation exists and he may even devaluate himself. He is sensitive to indications of such attitudes.

The following, of course, is simply indefensible behavior on the part of a professional. The incident occurred in another institution, but was recounted by one of our patient subjects:

> The most horrifying thing about this stroke was that my bowels and bladder were affected... the nurse came in with her little old bed pan... but nothing happened. Later, I turned on the light again... I waited and waited and finally the inevitable happened... In the morning, when the nurses came in, one of them said, "Disgusting". Well, I was disgusted and embarrassed and very uncomfortable. I said, "I had the light on and nobody answered." She said, "No, you didn't". I was just crushed to think she could possibly think I would rather dirty the bed than to use the bed pan.

3. Reasons involving consideration of a larger unit - the family and society

It has been noted, with regard to other critical situations, that professionals tend to take larger units into account when making evaluations than patients do. Sometimes these are units of time - the professionals give more weight to long-run considerations and feel that clients may neglect these in favor of more immediate concerns. But these units may also refer to persons. This last group of reasons reflects the fact that others beside the patient have an interest in his independence.

First, members of the patient's family may be adversely affected by the burden imposed on them. Much of what we shall have to say here could have been included under the heading "feelings of the client". But since the two sides of the issue, the feeling of being a burden and the feeling of being burdened, are so closely bound together, they were not separated.

In the first two excerpts quoted below, the emphasis is on the needs of those around the disabled person. A patient explained:

> I have very nice neighbors, and they will do anything for me. And I don't want them to think that just because of their kindness I want to take advantage and be calling on them all the time, so I will only call on them when I really need it... I feel that they've got their own things to do. Some of them work or they have got to go out for other reasons and I would only be taking their time.

This is different in emotional tone from the statement of a professional:

> It's hard on the people that have to take care of the person, and it's hard on the person...people don't want to have other people take care of them and the people that are doing it don't want to. Even though it's their job. And, well, then you can get into financially, how bad it can be for a family, or emotionally. If everyone is going to concentrate their efforts - if four are needed to take care of one, then other people are hurt in this area too, because then they don't get the attention that they might need.

The strain on both partners is described by this student;

> People might become very upset when they have to do for - like a relative, a wife who had to constantly care for her husband, even though she might be as loving and want to do it all the time, she'll still go through phases where she's discouraged. You know I have to do this, I have to do that, and it might become a task like cleaning house. Well, I clean my house, and then I bathe

> my husband...and he might begin to feel like an instrument rather than a person, because these procedures become very automatic... And his feelings, he probably couldn't express them quite as readily, because of the fact he knows that he's dependent on his wife. And so he has to kind of repress these and keep them to himself. Because after all he might feel he owes quite a bit to his wife for what she's doing.

She feels over-worked, he feels depersonalized, and the relationship between them is strained by his feeling that gratitude requires that he not express any negative feelings toward her.

The patient, quoted below, worries that it may be a sense of obligation, rather than really wanting to, which underlies the help of another, and that devaluative feelings may be concealed under a smiling exterior:

> You're always wondering in your mind how they really take it, by you asking them all the time. Even though they give you a grin, this don't mean anything. They can grin but they can still have a sneer under that grin, and this sneer is what I would be fighting... There are a lot of times you do something because you're asked, not because you want to do it.

We expected that the differences between professional and client attitudes with respect to independence might be more subtle than those we have seen in the topics previously examined. And the aspect we are considering now, illustrates this. We found quotations to illustrate that professionals are aware of the feelings of disabled persons about "being a burden", and others showing that patients are concerned about the needs of the one who is burdened. Yet, there remains a suspicion that differences do exist between the two approaches, that, as this social service worker puts it, the position of the professional requires that he take into consideration his responsibility to the larger unit - the patient and his family and the community:

> When the family is going to be that disrupted by having an elderly person in the home, when the whole home is going to have to change its patterns and revolve around this elderly person, I think then you've got to consider which is better - changing your whole life pattern or modifying it a

> little bit by placing this relative in a nursing home where his needs will be met. You can visit but you will not have the added stress of looking after the physical and emotional needs. And some of the elderly people can be very hard to live with and it puts a tremendous strain on the family... I feel I should be developing a broader outlook than just plain rehabilitation because this involves family and community functioning as well as the individual's.

The question of alternative recommendations about placement for the handicapped is a topic in itself, and not all facets will be explored here. But it is essentially connected with the question of independence. If one is not able to reach a given level of independence, one is threatened with being relegated to a nursing home, an outcome which is considered very undesirable. Professionals fairly often answer in this way, the question "What is there about dependence which is bad?"

> Very often families have a problem in terms of having someone around the disabled individual to take care of him and if they can't provide someone in the home continuously, that would very often mean that the patient would have to be put in a nursing or convalescent home, which very often isn't the ideal answer.

Only one patient invoked this reason, but the intensity of expression is worth noting:

> When a person can't walk up and down stairs anymore, and you have to have somebody help you, and they're not around, where is your independence?... I live with a brother that can't do anything for me. Nothing. And I've been in a nursing home... You feel as though all the people in the world are sick. So, what are we living for?

We will not, at this time, go into the many additional values which will be lost by nursing home placement. Certainly there will be additional limitations on space of free movement in this event.

There is one particular problem in connection with these matters which should be called to the attention of professional personnel. Sometimes the threat (though it was not called that) of nursing home placement is used as a motivating device, to encourage independence:

> A lot of times we can even use that as a motivational factor. We say, "You want to go home, but do you really think your daughter is going to be able to do all of the things for you that you say she can?"

Even in the absence of intensive study of the placement problem, one can see that there are possible dangers in such an approach. These anxieties of the patient are very potent ones, and cannot be lightly approached. What if success is not attained? Will the patient feel then that his placement outside of the home is a punishment? The consequences may be much worse and more permanent than difficulties in the professional-client relationship, they may even be disruption of the patient-family relationship.

The next category was one for which we have no clear examples from patients. But professionals do speak of the largest unit and say that our culture demands independence of us:

> Independence is rewarded in our society in general.
>
> We carry on our worship of certain puritan values...that have made this country...and we have merely introduced them into the field of rehabilitation medicine, and we continue to say that it is highly valuable for a handicapped person to become as healthy and as wise as he can by striving for the virtues of independent functioning. Other societies are much more lenient and people can be less healthy and more dependent... We believe in reinforcing the values of self-sufficiency. And we have equated dignity with the ability to earn a buck.

Society's interest in this matter is clear. To the extent that the handicapped are not independent, there is a danger that they will become charges upon the rest of us. It is no accident that public interest in rehabilitation of the handicapped began as an interest in vocational rehabilitation, since this meant "getting them off the welfare rolls". The next step was to upgrade the patient sufficiently in activities of daily living so that another member of the family was freed from the necessity of having to stay home and care for him. Then that person is able to earn the living for the family:

> If it's a man, for instance, and he has small children, even if he takes over the home-making role so the wife can go out and work, that's independence in one sense. It perhaps can keep the family off the welfare rolls.

Closely related to this category is one which emphasizes the status aspect of the traditional male role of breadwinner. We have already quoted a patient who felt that it injured his pride to have his wife working. And a student says:

> Independence for them would mean accomplishment, which is necessary for any human being, and success, and being able to maintain their former roles such as a man going back to being a breadwinner.

We have noted that the ability to earn a living is one of the two problems most often leading to devaluation of the client. Professionals are not immune to the tendency to identify what oneself strongly values with standards which everyone ought to meet.* There is an indication of such an attitude in a nurse who contrasts her own history of having worked since she was a youngster with the history of her patients:

> Some of them never worked in their life... How are you going to get them motivated to work now?.. I understand our main goal is to get this person back out into society as a useful individual. And, well, first of all it kind of amazes me to see so many people that don't work and never have worked, because I have worked since I was a youngster... Well, what we hear on the floor - over-hear most of the time because they usually don't tell us...this individual has no desire to work... If you were raised on ADC you don't

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*See "Adjustment to Misfortune", (3), for a discussion of "ought standards" and "asset-values". The latter are considered to be an asset when they exist, but are not required in order that a person be judged worth-while.

> have anybody to look up to that went out everyday and made a buck and brought it home and is proud of the fact that he worked for his money. Now how do you explain this (to your aides)...it upsets all of us.

And a social worker noted that:

> Our doctors...we pretty much know what their values are...they are work-oriented people. Many of them have struggled hard to get through school. And to have a person say "I don't think I want to go to work", would immediately bring out some hostility... which he would then impart to the team. "We've got an unmotivated lazy person on our hands who doesn't want to go to work."

Sometimes, it is a lack of acquaintance with classes other than his own which interferes with a professional's appreciation of the patient's position. A social worker recounts an incident:

> This man had painted houses on the outside and was just at a loss as to how he could translate this into something which would meet the limitations set by his cardiac condition. So the doctor said, "You know, I would organize a business, and I would get some people to work for me. And I could get on the phone and call...and arrange jobs". And so I said, "Well isn't that wonderful! You know, you're a doctor... and you have an I.Q. of so and so. That's wonderful, but this guy, after all"... So many doctors have practiced in very limited settings... We're not dealing with people who have been exposed to our way of life... They can't even begin to vaguely imagine what it would be like.

What the young professional has to realize is how combinations of circumstances may operate. Being disadvantaged with respect to race or intelligence or social history to begin with, and then to have a physical handicap superimposed, may be too much to overcome.

Reasons for Allowing Dependence

To see genuinely positive aspects about dependence, is very different, psychologically, than to realize that there are certain conditions under which dependence may be allowed, or that it is sometimes necessary to yield to dependent patterns. Therefore, these two sets of statements from subjects are separated. Table X summarizes the reasons for sometimes allowing dependence.

1. Given circumstances which are the inverse of reasons for independence

It is hardly necessary to document the fact that dependence is "all right" and should be permitted when the severity of the handicap makes it necessary. As professionals say:

> I don't mean that we should be tyrants and insist that people do what they are too sick or ill-equipped to do.

To the patient also, help is acceptable when a particular task is beyond his capacity, or a particular goal will be otherwise inaccessible:

> If I go to any big doings, I have to have some help to get into the car... I know it's vital to have somebody near in case of wet pavement... If I had to have help, that's different. But when I can do it myself, I try first.

Included in this category, also, are those instances in which "safety" is stressed. Professionals, especially, noted that it is sometimes safer for patients not to try to be too independent. These reasons for allowing dependence parallel, and are the inverse of reasons for independence. In other words, under some circumstances, help from another person adds to space of free movement and adds to security.

Similarly, the next category is little more than a miscellaneous collection of instances which are the inverse of various other reasons given in favor of independence. For example, it was stated that dependence is all right if pity (i.e., status) is ruled out. Or help is acceptable when there is no question of being a burden.

> (When) you yourself know that you are trying very hard, but as long as someone is nearby and you're not putting them out of their way and they are willing.

One of these "inverse" situations is interesting because it illustrates that not all of the professionals are so concerned

Table X

Showing circumstances under which dependence may be allowed.

Category	Number of subjects using a given category.			
	Clients	Professionals	Students	Total
1. Circumstances which are the inverse of reasons for independence:				
a. When necessary because of degree of disability, or for a particular task; for safety.	15	7	12	34
b. Other (e.g., burden ruled out).	3	4	1	8
2. Temporarily; in the beginning stages.	4	2	3	9
3. Given certain patient characteristics:				
a. Old age	0	7	6	13
b. Dependent life-style	1	11	8	20
Total "dependence permissible"	23	31	30	84

about regression that they insist on every possible opportunity being taken to practice what has been learned. This professional, for example, feels that when the necessity for learning is not a factor, when the task is one that has been already mastered, the difficulty and the amount of energy required can be taken into account:

> Once they get along, and if...they know what they're able to do and it's difficult for them...I see nothing wrong in asking for help just for the effort saved, because they have to consider their energy, too.

2. Temporarily; in the beginning stages

The next category emphasized the temporariness of the situation. Dependence is permissible in the beginning stages in order to build up confidence, to guard against failure. A student O.T. suggests:

> He might need a lot of support and encouragement in the process of learning...not pushing too fast or too hard...and we don't want to give him too many failures...build up his confidence.

The initial period of hospitalization is indeed a touchy one. Many complaints of the patients about difficulties in their relations with professionals on the issue of independence arose in this initial period. According to this patient:

> I'ts just a phase of your illness when "Oh I'm so ill somebody has to help me". That's the way you feel when you just are coming out of that... But then you go along and see how you are doing, then it changes your whole attitude.*

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*Part of the difficulty in the past was a lack of orientation. Orientation is a separate topic, but because of the implications for independence, it deserves mention.

A patient spoke of the difficulty of the transition from a general hospital to a rehabilitation hospital:

> In the General Hospital...I took life easy and enjoyed it and became quite spoiled. The day

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*(footnote continued from previous page)

> of reckoning came, though, when I was transferred to the new hospital. Their philosophy was that the more you did yourself, the faster you'd recuperate. I agree now, but there were times the first week or so that I would have walked out of there if I could only have got my bum legs to cooperate.

And a nurse was also much concerned about this:

> A patient who has never been in here has absolutely no understanding of this place. They whys and wherefores. And this is the reason why, in the beginning they think of us as some kind of monster. Because we insist that they do this. A patient who's got two good hands, why can't she pull that dress over her head. The reason why is because she came from the other hospital and they were dressing her completely... And this has to be explained in the beginning over and over and over again... "This is a rehabilitation hospital, we are not here to wait on you hand and foot; we are here to help you help yourself and the only way we can do this is insist that you do it. So, you don't do it so good the first time, the next time you might do it a little better..."

Patients are not the only ones who lack knowledge about rehabilitation and therefore need orientation. The same nurse quoted above mentioned that families do not understand the hospital's purpose and "feel cheated" because insufficient "service" is given. And the quotation on the first page of this chapter referred to the fact that families sometimes undo that has been done by the rehabilitation team, by "coddling" the patient when he is at home.

It was felt that an orientation booklet could reduce difficulties in professional-client relationships by narrowing the gap between what the patient may expect, because of his conception of a hospital as a place which gives maximum care and service, and what will actually happen in the rehabilitation program. Such a booklet was recently introduced at Schwab Hospital, and it will be important to follow up, to see how much is achieved thereby, and the extent to which it will have to be supplemented by personal communication.

3. Age and life-style

The remaining conditions which determine the permissibility of dependence have to do with certain patient characteristics, age and life-style. These categories were virtually unused by patients.

We have remarked upon age as a determinant in the opening pages of this chapter. Statements from professionals about this as a condition modifying recommendations, were so much alike, that one almost came to expect a certain sequence of phrases: "not cramming it down the throats" of "little old ladies" or "someone who has worked hard all his life" and is conntent to sit back and be waited on". It is easy to agree with the professionals' feeling that these persons "have earned the right" and "if that's what they want, why not let them enjoy the years they have left". But the very frequency of repetition brought up certain questions for which there are not entirely satisfactory answers: Can this sometimes be an excuse for the professional's avoidance of cases where success does not seem likely? And should one "cram it down the throats" of the young? We shall return to the first of these questions when we address ourselves, in Chapter V, to questions concerning admission policy, the "elite" patient versus the "hopeless" case. We shall attempt to deal with the second later in this chapter, when we consider "how much to push" toward independence. Part of the answer is given in the next category.

The category dealing with the "life-style" of the individual is evidence that there is something besides age which should be taken into account in deciding which individuals should be pushed toward independence. As a student nurse said:

> She refused to do just about everything, because she said, "Well I'm going to have help with this... I never did that". For a person like that...she's had all this help before. So why make her do it now?

A professional who emphasized the "life-style" qualification showed how failure to take this into account can lead to great difficulties between professionals and clients:

> There are some human beings who have never been independent...who have arranged their life-style and their life relationships so that they have either remained dependent on parents or on some family member..and when these die out they have arranged to continue

> their dependent role by finding...some welfare structure to continue their needs... Now, if such individuals lose a leg...or become arthritic...we find them as very dependent characters. You must consider this a part of their normal style of living. And we can push all that we want, they will resist as hard as they can... We can get involved in...mutual hostility and get nowhere. In some individuals, then, we yield to their dependent patterns.

What one strongly feels about this whole group of "permissible" kinds of dependence is the reluctance of the professional to depart from the accepted values, as in this statement that one can't force independence:

> He feels that he is disabled and that he can't work and he is unwilling to work. So we get into this kind of thing, where we can make recommendations, but we can't force the horse to drink. You can just bring him to the water.

And thus it is that they try to limit dependence to conditions under which it is strictly necessary, or for temporary periods, or in the case of some individuals, yield to the dependent pattern. Only with the references to the aged is this negative feeling absent.

Positive Aspects of Dependence

The positive aspects of dependence are shown in Table XI. These were seldom given spontaneously. When positive aspects were elicited, it was seen that patients stressed the first three categories, all of which recall Chapter II, on "Involvement", in that warmth and interest are emphasized. Professionals tended to stress the last two categories.

1. Dependence and warmth

Even without intensive probing some patients would mention the connotations in the dependency relationship of warmth and regard and interest. It indicates that someone cares, and shares your difficulties. A woman who had admitted her dependency needs explains:

> You have to feel that you have somebody to depend on. This woman...she needs more

Table XI

Showing positive aspects of independence.

	Number of subjects using a given category			
Category	Clients	Professionals	Students	Total
1. Means warmth, regard, interest, "someone cares".	4	1	4	9
2. For immediate needs, "on bad days".	4	1	0	5
3. To protect close relationships; "for their sakes".	4	2	4	10
(Acceptance of Interviewer's suggestion.)	(2)	(3)	(2)	(7)
4. Avoiding rigidity; acceptance of handicap.	1	5	6	12
(Acceptance of Interviewer's suggestion.)	-	(6)	(2)	(8)
5. Reasons which broaden the concept; "no man is an island".	2	5	4	11
Total positive aspects	17	23	22	62

> love, warmth and affection, caring. And to a certain extent we all need that, especially women... I think it gives you a lift to receive help.

Even the man patient who we quoted previously as not wanting his wife to work, added:

> I'm proud that she is doing what she is doing for me. It shows me that she cares. It's just the two of us now, and we're really together to share it either way.

One of the few professionals who spoke spontaneously of the positive aspects of dependence was a student nurse, who added to her statements about the virtues of independence:

> Dependence can be a way of showing love and acceptance, too, and so you can't look at one without looking at the other.

2. For immediate needs

In the next category, the emphasis is on the immediate needs which have to be taken into account. Help is welcomed "on bad days" or "when you're depressed". It differs from a previous category emphasizing temporariness because it is not just help while learning which is involved; one sometimes needs "a lift" even after a task has been learned. It also differs in that a definitely positive quality is seen. These are two patients speaking:

> There are times when you get depressed... and sometimes just a little hand goes a long way... not every day, but once in a while it does make you feel good.

> There are times when you are able to do many things, and there are times when you can do them but, either because of the weather or because that day is just not a good day for you...you are not able to do as much as you did the day before. And you ask for help and they tell you, "Well you can do it yourself", but you know that you can't do it just then... One little push is all they need to keep going. While if they are refused that lift or that push or that hand, they may not be able to continue.

It is not surprising that only one professional is included in this category. We have seen in previous chapters that professionals focus on long-run goals. In doing so, they do not appreciate the client's immediate need for "a lift" or do not see that this can be considered by clients as an indication that "someone cares". The one professional indicates that taking immediate needs into account can even have long-run benefits:

> There are times to indulge that. Even when you're working with a patient for independence... Just telling somebody to rest, or letting them do something that they get pleasure from doing, rather than constantly pushing them, you get a much better response in the rest of the hours. So you've really not wasted time, but rather gained a bit.

3. To protect close relationships

The third category also is related to the closeness and sharing meanings of dependence, but here the emphasis is on the feelings of the donor of help. The disabled person will accept help "for the sake of the other". Several patients alluded to this:

> When it's someone that might feel bad if you didn't accept their help, because they figure that you might be thinking that they want to help you out of pity or sympathy. Just like your mother or parents - now you turn down their help...then they might feel bad about it.

> Amongst friends, sometimes they want to do a little something for you when you are trying real hard to do something and you're frustrated. Sometimes it bothers them because they're watching you trying to do it... Once in a while it's alright to accept a little help that way.

In early interviews, so few professionals made use of this category that the experimenter adopted the plan of suggesting that possibly a too great stress on independence by the handicapped might affect close relationships in a negative way. People who care for each other want to do things for each other and might be hurt by refusal of their offers.* There were indications that this viewpoint was accepted. When it was clear from the subject's remarks that it was accepted (with more than a nod or a very brief remark), this was indicated on the tables as "acceptance of interviewer's suggestion". In some cases, useful additional material was thus elicited, as in the following excerpt:

> (I: We wondered whether violence was being done to close, affectionate relationships, in which people are mutually interdependent and usually ask for and give help on occasion. And whether dependence might have some positive aspects in addition to just being allowed. Whether in the context of warm, affectionate relationships, maybe something would be lost if one stressed extreme independence?)
>
> S: We have to stress with the young people that there's nothing so terrible about dependency. So you need other people's help now...there is a two-way street. To give is to receive... Naturally, the well person who now has a paraplegic son or daughter on his hands, will at times be tied down... frustrated. That doesn't mean that he doesn't want to continue giving to the loved one... Say to the patient, "It would make it easier for everybody if you accept the dependency that you are now forced into... Don't make it harder on other people by fighting it. You merely add a tremendous load of stress and discomfort...by not rolling with the punch. You are constantly expecting your family to come forward with reassurances and repeated statements that you are still part of the family and we love you as you are."

This particular excerpt is again a transitional case which partakes somewhat of the next category, having to do with avoidance of rigidity.

4. Avoiding rigidity

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*This, of course, was done at the end of the questioning regarding independence. (See Appendix II.)

The observation that rigid stress on independence might be harmful, was seldom a spontaneous offering of the subjects in response to general questions about independence and dependence. One instance in which this did occur was in the record of a psychologist:

> I don't like to see any characteristic be (too) consistent... I suppose the trick of the whole trade is to hold independence high and recognize when independence can be damaging, and under those circumstances ask or invite the assistance of other people.

Since this subject had laid great stress on denial when discussing other issues, the interviewer asked whether there was a connection between great emphasis on independence and accepting a handicap. His response was:

> You're certainly right. It ties in with acceptance and denial... What it amounts to is getting the patient to perceive themselves as they really are.

This category is of course closely related to the category that dependence is permissible when it is a matter of necessity, a category which patients did use. The distinction is in the added element of self-acceptance, which is positively evaluated. There were no clear illustrations from patients that it is part of a good adjustment to handicap to be willing to accept the fact that some degree of dependence is necessary, to be willing and able to ask for help when it is required. Professionals could be led to consider this aspect:

> (I: Now is there anything good to be said for dependence at all?)
>
> Dependence in the sense that if a patient can recognize his limits and can accept them and become dependent to the point where he has to, certainly. If you think in terms of realistic self-appraisal, yes.

An O.T. student explained why extreme stress on independence would be undesirable:

> Because I think a person could be hurt if they try to make themselves...into a piece of metal...so hard that it would just make a person brittle.

5. Reasons which broaden the concept of independence

Finally, in seeking for something positive which they could say about dependence, some subjects found it necessary to broaden the concept considerably. They departed from the idea of independence as the ability to accomplish physical tasks alone, sometimes falling back on philosophical ideas of the "no man is an island" sort. One patient expressed an idea of this sort:

> You don't say you don't want to be dependent because you've got to depend on somebody.. You can't live in this world alone even if you're not handicapped. So don't get the feeling that I don't need anybody, I can make it on my own, because you're wrong there.

The other instances are all from professionals:

> We operate in a democratic society. Therefore, it is necessary to invite the assistance of other people. Sometimes, only for political reasons, and other times, for the actual necessity of getting things done.

Or students:

> If an individual is so totally independent he feels he can function without anyone, whether it's in a rehabilitation unit or in the outside world, I don't think this is good, because personally, I feel that people need one another even if it's in small ways. And to be totally independent, is like living, you know, one man on an island. And this isn't it - any extreme is not good.

This, then, was the extent to which subjects could see positive aspects in dependence. There seems to be a heavy preponderance of positive evaluation on the independence side from both groups - clients and professionals. But clients seem somewhat more ready than professionals to see that dependence can connote a warm and affectionate relationship, and that momentary lapses from strenuous effort to achieve independence may be necessary "on bad days"; or that "a helping hand" gives one "a lift" when he is depressed. The professionals, on the other hand, were more likely than patients to see that extreme stress on independence may have implications for adjustment, that it is possible to be too rigid, that inability or unwillingness to accept help may mean that one does not "accept" his handicapped state.

Unacknowledged Dependency Needs

There is one further category which was not included in the tables because it is an equivocal one. One might have included as a reason for independence, that it is positively evaluated as a defense against giving in to deep dependency needs. This means, of course, that on the deeper level it is dependence and not independence which is really desired.

The evidence for this category, then, is apt to be indirect and a matter of reading between the lines. For women, this is not so pronounced a problem. Our culture will allow them to assume a dependent position. We have seen in the first pages of this chapter that there were two women who openly admitted their dependency needs. And in the case below there is only a thin disguise. This woman had difficulties in co-ordination as a result of cerebral anoxia. She had been complaining that, because she is ambulatory and her handicap is not immediately visible, people expect too much from her, and added:

> Well, of course anything I can do for myself, I do. I want to be as independent as possible, but I do find that because I am this way, maybe I don't get the attention I should get.

From men patients the closest one can get to evidence on this point are statements that there is a temptation to get lazy and take advantage of their position:

> It's just human nature. After awhile, you get so you don't do anything for yourself. (You) become more of an invalid than you are.

Usually they are only willing to state that others, not they, give in to this temptation.

> Some people use it as a weapon, and accept your pity and sympathy for a way of life.
>
> Some can wheel a wheel-chair as well as I can, but if there is someone else around... they would want them to wheel it, and they ride just like a baby. It's fun for them.

The other indirect evidence on this point consisted of occasional complaints by patients that staff (especially non-professional personnel) do not *appreciate* the difficulties of the patient, that what can be done so easily and without thought by normal persons, is a matter requiring considerable effort on the part of patients.[*]

Even from professionals, however, direct statements on unacknowledged dependency needs are few. Only the most sophisticated mention that one reason for evaluating independence highly may be that "I am apparently a very dependent person who defends rigidly against dependence needs".

The connection between this matter and the question of status and devaluation was described by a psychiatrist. The interviewer had noted that injured soldiers[**] had a tendency to say "I only want help when it's absolutely necessary".

> This is a very homogenous group...which of course would weight what you would hear from them... It would weigh heavily in their self-concepts. We are fighting men, trained to be self-sufficient...(with) over-emphasis of masculine independent capacities... They cannot see themselves as being married and relating to a woman from whom they would accept something... (They) are reacting to their immediate situation by "I'm no good, I'm damaged, I've got only one leg, what woman is going to want me? I'm going to have to live by myself, do everything by myself." They over-emphasize by reaction formation, their individual capacities to live, to function as men, to work, etc... Not only this but over-compensation. I am really independent and I am really tough in spite of the leg. They, too, are defending their great needfulness. And if it was difficult for me

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[*] This complaint is not without foundation. A resident in physiatry who is also the husband of a severely handicapped woman recommended that every therapist live a month in the home of a person who is disabled. Then they might see how some suggestions are impractical, and not something that a person "really would have enough gumption to do every day."

[**] Subjects in a previous study (9).

> to admit my own deep dependent needs, it's difficult for these guys who were fighting men.

Preliminary Recommendations

The great value which professional and clients place upon independence is a potent force motivating rehabilitation progress, but a different viewpoint about the alternative is required. The belief that independence is a self-evident good and you can't have too much of a good thing, may lead patients to take, and professionals to reinforce, attitudes which are not in the direction of optimal adjustment.

Our first recommendation concerns the relative absence of positive evaluations of dependence. In teaching rehabilitation orientation to students, we appear to have neglected to mention these aspects. Nursing students, in particular, mention that they have to guard rigidly against a tendency to "mother" or "over-protect" patients--a natural inclination of those who are attracted to the helping professions. They may, then, go too far in the opposite direction.

The value of dependence was pointed out by Dr. Beatrice Wright (12) in the context of teaching independence to children in various cultures: "Dependence in itself is a value; it is essential in many important kinds of inter-personal relations. People, for instance, should be able to rely on others, to ask for and accept help, to delegate responsibility, but these relations occur naturally only when the person has learned how to become dependent... Independence must be viewed in terms of the balancing framework of constructive dependency needs... the priceless quality of warmth in inter-personal relations may be usurped by the calculated zeal to teach the child independence." And what applies to the child, who has the possibility of an optimal degree of independence before him, applies no less to the handicapped adult who may never be able to regain this optimum.

It seems to us that there is insufficient awareness in many young professionals of the danger, in some handicapped individuals, of too great a stress on independence. Some clients so rigidly guard against their dependency needs that they are unwilling to accept help in any save the most extreme situations, and view even these necessary occasions with loathing. In these circumstances, the professional might reinforce what amounts to a denial of the handicap. Failure to "accept" the handicap has these consequences: self-devaluation; imposing on themselves much more strain than would the normal person who readily accepts help to save time and effort; imposing a severe strain on those about him, who are forbidden to help in ways natural for close persons. There is a tendency in those who do not accept their own dependency, to require from those around, enormous doses of reassurance that they are still loved and wanted.

The second set of recommendations is about when and how to push toward independence. It would be wrong to say "never push". Even a patient who strongly emphasized the client's right to control his own life, said:

> (If) he won't do nothing or he refuses to get out of bed... I don't think he should be just scratched off the list... (If) they seem to have the feeling they don't care, I don't think they should just turn them down or let them go because they refuse it. I think they should try to push them a little. And try to let them know how important it is...to be independent.

And a woman patient, one of the two subjects not averse to being dependent, also said:

> I think the doctor or therapist knows what's good for them and should urge them on. But they shouldn't force them. They should be allowed to take their own time in making the step. But they should be urged. The reasons for it should be pointed out.

But here, as in giving information about medical condition and prospects, going slowly will be beneficial. First, because the process of orientation is not a simple one. Time is required to narrow the gap between what the patient may expect because of his conception of a hospital as a place which gives maximum care and service, and what will actually happen in the rehabilitation program.

Secondly, a slow start gives the professional time to evaluate the extent of the physical disability:

> You can frustrate a patient very badly... You have to be pretty careful in assessing his potentials, that you don't expect more from a patient than they can give you... I've been guilty of it...(when) a patient looks more alert than he actually is...

> And then you place higher expectations and you have to back-track. And it's much harder, then, to establish rapport and work through all of the basic things that should have been approached first.

What was said earlier about the importance of guarding against too many failures in the beginning, is pertinent here.

Third, the professional will have time to get some indication of the kind of personality he is dealing with. The warning that pushing a dependent personality will only lead to resistance, or even hostility, is important if the intent is to minimize difficulties in the professional-client relationship.

This nurse indicates the need for a slow, step-wise approach, setting intermediate goals, and with lavish use of praise for attainment of these:

> And if they can't, then we proceed to teach them so that they can. And my girls (aides) ...if I see that they are pushing a patient before the patient is really able to accept it, I try to slow them down a bit, because they get kind of over-anxious sometimes with a patient. But it amazes me how much they can get the patient to do with a little bit of badgering. And then, when they do attain that little tiny goal, then they tell them how well they've done, and they praise them.

The third group of recommendations involves the tendency of the professional to deal with larger units than the patient usually does. We do not suggest that the professional neglect the larger units, but merely that he recognize the difference in the approaches and that caution may be called for. The unit may refer to time. As was true about other issues, the professional takes a longer-range viewpoint. He may be so concerned with the possibilities of regression if every opportunity to practice skills is not utilized, that he fails to take account of the patient's momentary needs for a "lift" on bad days. The desirability of an occasional relaxation of strenuous efforts is not seen by these persons. Nor does he see that recognition of these needs may be taken by patients as evidence that "somebody cares".

Sometimes consideration of the larger unit means weighing and balancing the needs of the patient against those of the rest of the family or against the interests of "society". Although patients are not entirely unmindful of these interests, no patient used expressions like "disrupting the family" when "four are required to take care of one", or "getting them off the welfare rolls". When society's needs are stressed by the professional, there is a danger of the patient seeing this as devaluation because of his inability to meet those demands. When the family's needs are stressed, then there is a danger that the patient will feel, "He is thinking more of them than he is of me."

Extreme care should be taken about using as a motivating device anything that smacks of a "threat", (e.g., that failure to achieve independence will result in nursing home placement).

The last group of recommendations concerns the values of the professional. Professionals seldom admit devaluative feelings toward those who have not the capacity to achieve independence, but they are not so reluctant about expressing such feelings toward those who have not the desire. This means that they might tacitly convey their attitudes to those who are dependent personalities, or to those who, because of multiple disadvantages - social as well as physical -, give up the struggle. There is no lack of good will necessarily implied; there are those who, simply from a lack of experience with milieus other than their own, don't see "why can't they be more like me". Not all professionals guard against the tendency to impose one's own values on others, as does this O.T. student:

> You can value it for yourself, but you
> can't put your goals on somebody else,
> your beliefs.

It is suggested that the young professional in training be helped to see:

(a) That his own values are not universally held, especially not in less acquisitive and less aggressive societies, or among the more disadvantaged groups in this society.

(b) That there is a distinction between values which are an asset when they exist (but which are not necessary to the judgment of a worth-while human being), and "ought" values - standards which everyone ought to try to reach.

(c) That one can set high goals for himself with respect to a multitude of value scales without necessarily imposing these ideas on others, or devaluating non-possessors.

All of this is compatible with demonstrating ways to achieve greater independence and allying oneself with that independence which "is the goal of the human spirit" according to both clients and professionals.

Whether he is able to accept these attitudes or not, the scrutiny or reassessment of his own values by the professional student may have consequences. He may be less likely to add to suffering by betraying devaluative attitudes to those who lack what he possesses. He may, in the absence of those specifically trained to handle negative and self-devaluative feelings, be able to indicate to patients plagued by such feelings, that there are alternative ways of viewing the independence-dependence issue. He may, at the very least, be made aware of the necessity for caution in using "motivating techniques" which could possibly increase the anxiety of the patient about being "no good" or a burden.

Summary

Patients and professionals acknowledge these positive values of independence:

The convenience of being able to reach desired goals.

The satisfaction of self-determination.

The security of knowing one can handle emergencies that may arise.

The self-esteem that comes from knowing one is able to do what others normally do.

The maintenance of privacy in matters of personal hygiene.

The sparing of others - leaving them free to pursue their own goals.

Avoidance of all the other negative feelings connected with the idea that one is a burden (e.g., the fear that others may be resentful).

While members of both subject groups readily admitted that there were situations in which dependency might be allowed, it was difficult to elicit positive aspects of dependence. Yet a too rigid adherence to independence may adversely affect relationships with close persons who want to express their love by doing things for the patient. And it may not be the best adjustment to disability to impose more strain upon oneself than would a normal person, who readily accepts available help to save time and effort.

Superficially, there seemed to be a good deal of agreement between professionals and clients on the issue of independence versus dependence. Yet, on close examination, many kinds of conflict are seen to be possible. The very fact that independence is so highly valued implies the possibility of devaluation of those who cannot or will not achieve it. And perhaps the fact that dependency needs are so often not acknowledged, contributes to conflict.

It is the conclusion of the investigator that the great value which both professionals and clients place upon independence is a potent force motivating rehabilitation progress. But a somewhat different orientation is required about the alternative. The belief that independence is a self-evident good and "you can't have too much of a good thing", may lead patients to take, and professionals to reinforce, attitudes which are not in the direction of optimal adjustment. Independence should be seen as a great asset when it can be achieved. It need not be considered an "ought-standard" which everyone must attain if he is not to be devaluated.

CHAPTER V

Other Critical Situations and Suggestions for Further Research

Within the time limits of the pilot period, it was not possible to analyze all of the critical situations encountered. This chapter will be concerned with unfinished tasks and with suggestions for further research. The sub-sections to follow will deal with: a) analysis of other critical situations encountered in the rehabilitation hospital setting; b) the necessity for further investigation of determinants underlying reasons for choices; c) the desirability of investigation in another type of setting, to increase the roster of kinds of critical situations seen and to determine whether the findings of the pilot period are limited to the setting studied or apply generally; d) an inquiry into the viewpoints of teaching personnel; e) longer-range research.

The topics of involvement versus emotional neutrality, hope versus reality, and independence versus dependence, illustrate the way in which qualitative analysis can yield useful information about the divergent viewpoints of professionals and clients. It has been argued that clearing up misunderstandings, even on the overt level, may do much to eliminate unnecessary conflict in professional-client relationships. We would want to apply the same method of analysis to other problem areas. Data already gathered permit us to indicate the scope of the problem in four additional critical situations having to do with control, safety, candidates for rehabilitation, and placement after discharge.

Control Vested in Professional or Client

The general problem was as follows: whether (or in what respects) control should be vested in the hands of the professional; or, instead, more opportunities should be allowed for decision-making by patients. In the study of Ort, Ford and Liske, "The Doctor-Patient Relationship as Described by Physicians and Medical Students", (11), control was seen as the nucleus of the doctor-patient relationship. The physicians who were subjects of that study felt that the doctor should be the dominant participant in the relationship, and the patient should cooperate. The doctor's authority was called "rational" because it is based on the doctor's special knowledge, and "legitimate" because it derives from the patient's consent.

On the other hand, Rusk is quoted* as saying that the "fundamental choice must be the individual's own, not that of the host of people whose knowledge and skills qualify them to help but not to direct him." Self-sufficiency "cannot be nurtured if it is denied at the outset."

The *spectrum* of professional opinion in the current study, includes those who felt strongly that control should be in the hands of professionals. There were also those who reluctantly said that "of course the final decision must be in the hands of the patient; you can lead a horse to water but you can't make him drink", (which implies a wish for professional control). Some stressed the necessity for genuine co-management. Finally, there were those who resented the patient's being "pushed around" and not consulted on matters about which he is very much concerned. Patients also varied, from those who said, "You must be obedient", to those who resented having things done *to* them, who said, "This is *my* life, let *me* decide."

The *reasons* in favor of control by the professional were primarily his greater knowledge, and the presumed tendency of the patient to neglect long-run goals in favor of more immediate considerations, like discomfort. Some reasons were connected with safety, and will be considered separately. Lack of time, and the necessity for having regulations in any institution, were contributing reasons.

There were two chief reasons for giving more opportunity for decision-making to patients. The first has to do with the patient's dignity and rights and feelings. According to a professional:

> Institutions strip patients of dignity.
> They are shoved around like cattle.
> Making decisions restores self-respect.

And a patient asks:

> Treat me like the adult I am. I am not a child, not psycho, not in prison.

The second has to do with what Rusk called "nurturing self-sufficiency":

> If independence is good, you want him to

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*By Eustace, (4).

> assume more responsibility.
>
> They get out of the habit of making decisions.

Another reason, having to do with lessening friction between professionals and clients, was sometimes mentioned, and was often implied when giving recommendations as to *manner* of behaving, (e.g., "ask, don't order," "take time to explain why you must do it and listen to the patient's side").

A great variety of *specific situations* are encompassed in this very broad topic, and the nature of the situation has much to do with opinions pro and con. When the decision concerns something as vital to patients as elective surgery, then both groups agree that "of course" the final decision must be left to the patient or his guardian. There are legal safeguards of this right. With decisions concerning management of a case--such matters as diet for diabetics, and taking prescribed exercises--there is a tendency to favor control for the professional. The patient's co-operation is usually necessary in carrying out the procedures decided upon.

Instances which most often led to dissatisfaction, could be generally described as those which the patient feels are solely matters of the *convenience* of the institution. They are matters which patients felt that they could have a voice in, without in any way hindering their rehabilitation progress. (For example, the question of being moved from one room to another; that appointments are made for a patient without his being notified; that lights are turned out at a certain hour, so that a patient cannot read until he is sleepy, etc.)

One such question was solved to the great satisfaction of the patients when the "independent traveller" idea was introduced at the hospital studied. Each patient is now evaluated as to judgment and ability to get about on his own. If he is considered a good risk, he is given a green wrist band which allows him to use the elevators at will. The medical director commented on the success of the new procedure:

> (There was) resistance from some of our professional staff when we first talked about this, because it was new... The program has done exceedingly well. Nobody has complained. There have been no accidents... The patients have gained because it takes us back to this independence business.

The success of this step in the direction of a therapeutic community encourages the belief that more like it would lead to improved professional-client relationships.*

Safety First Versus Taking Risks

Related to the control issue is another which can be stated as follows: whether it is best always to "play safe" or whether, under some circumstances, one can justify letting the patient take risks.

The value of human life, as may be expected, is given the highest priority by medical professionals. So we can expect to see this reflected in the positions taken with respect to this issue. And, indeed, most subjects (professional and client) strongly favor "safety first." The professionals may say that this is "my duty," or that taking risks which affect patients is "immoral." The patient, having lost some assets, is naturally concerned with guarding those which remain. In addition to the protection of the patient, "playing safe" involves, also, a protection for the professional, who would be blamed if an accident occurred, and a protection for the institution, which is legally responsible and has insurance rates to consider.

There was a feeling that patients may not sufficiently understand what may be hazardous; and so even patients who wanted more opportunity for decision-making in other respects were willing to defer to the professionals in matters of safety regulations.

At the same time, there is a disposition on the part of some to weigh and balance possible risks against advantages to be derived from a less cautious attitude.

The advantages were, again, mainly in terms of the self-determination of the patient. It was said that normals vary in how much risk they choose to take, and patients should have the same rights. Some important provisions usually accompanied these statements: This is reserved for those whose judgment is not impaired. The professional has a responsibility to warn of possible danger. Often, also, this distinction is made: "When you go home you can, of course, do as you choose, but while you're here (in the hospital), I have to insist that you observe these precautions."

Other advantages were mentioned which apply in situations when the risks are not too severe (e.g., a possible fall in re-learning ambulation). These were: the likelihood that one can also learn from mistakes; that "learning to take the bumps is part of it"; that if the patient is over-protected, he won't know his actual ability; that a therapist has to know when to "let go". It was even said that the patients of the best therapists are apt to have the most falls, and that the patients most motivated for independence are the most likely to take risks.

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*Kutner, (7), has described other such steps.

It would be useful in exploring this topic to include cardiac patients and professionals treating them, as this question is apt to be very potent for such persons. For instance, it was pointed out that some cardiacs think, "I'm going to die anyway and I want to make all the money I can for my family," so they want to take risks contrary to their doctor's advice. The opposite also holds; there are those who are too fearful to take the steps which professionals would urge. In other words, the answer is not whether more or fewer risks are desirable, but how to obtain more correspondence between professional and patient outlook.

Candidates for Rehabilitation

Questions sometimes arise as to whether time and rehabilitation resources should be invested in patients who can only be slightly upgraded, or whether preference should be given to those who are most likely to profit therefrom. Actually there is a cluster of different questions here which will have to be clearly separated. One is related to the amount of functional improvement which is possible with a given medical condition. Is rehabilitation worthwhile when the degree of improvement at best will not be very great?

The range of opinions among professionals was striking. For some it was a self-evident matter that patients should be accepted "even if there's no opportunity for advancement, if it's just maintenance at a particular level to prevent them from deteriorating...I don't think society should stop and ask about the cost of this when there's so much being spent on much less worthy causes." For others, it was just as clear that some patients shouldn't be admitted for rehabilitation, that they are "socially and emotionally as well as physically disabled" and that, since you can't do anything about what he's going back to, it's "time and money wasted", and it "makes a mockery" of the professional's job. The consensus seemed to be, that patients who are expected to be only minimally improvable should at least be admitted for evaluation and given a chance; because even slight upgrading in ADL (activities of daily living), may make a difference to the patient's self-esteem and to the willingness of his family to have him come home.

A separate question deals with the worth-whileness of investing resources in unmotivated or unco-operative patients. Even patients sometimes see this as a determinant:

> I can see their reasoning--if the patient won't cooperate there's no use fooling around and taking up space when somebody needs it more.

But other patients plead that this criterion not be applied too strictly:

> (Some patients) seem to have the feeling that they don't care. I don't think that they should just turn them down or let them go because they refuse it. I think they should try to push them a little, and try to let them know how important it is... to be independent and to do the things that in the long run will get them there... Just because a patient refuses therapy sometimes or is hard to get along with, I don't think he should be just scratched off the list.

Another question concerns age and life-expectancy. Is rehabilitation worthwhile when the improvement will be only for a few years? One professional said:

> With some, I feel futile, I lack motivation. You could get improvement if you work doggedly, but if they're in the 70's and content, what's the point? There are so many in the 30's and 40's who need help.

But others were vehement about using this as a yardstick:

> I'm not willing to buy the old age statistics which really are pretty poorly collected anyway at this point. There is a lot about aging that isn't really consistent with the "little old lady" picture that statistics have given us in the past. Some little old ladies at age 65 are riding bicycles, while others are sitting in nursing homes being fed intravenously. So it is very important

> to assess the individual. We offered to... create a special (psychotherapy) group for regressed people. And, lo and behold! After only two or three sessions, the patients began to blossom and participate in therapy... Three out of five were more cooperative on the floors, and the whole staff was becoming more motivated themselves to help these patients."

In the chapter on independence, we have already referred to the fact that the commendable attitude of not "cramming rehabilitation down the throats of little old ladies", may sometimes be used as an excuse for professionals' avoiding cases in which success seems unlikely. There was frequent allusion to the fact that part of professional gratification lies in successful accomplishment, that they are frustrated by failure to achieve the goals they set, that they tend to get more involved with those they feel have something to offer, and that they tend to avoid situations in which they would feel unable to produce significant improvement. But predictions about the likelihood of success are not always correct.

> No professional person wants a patient they can't be successful with. And if they predict in their own minds that this patient is one I know I never had success with... why should I spend a lot of time. Get them out of here and bring in somebody who will fit the mold or kind of patient that I can deal with best. Which in a way makes sense. You can't blame him for that. But on the other hand, it does present a problem when you are attempting to rehabilitate the patient who is sent here. And they can be rehabilitated beyond what their prediction may have been.

If this is true in a rehabilitation hospital, the problem must be many times magnified among those professionals who are not knowledgeable in this field:

> If more physicians were knowledgeable about some of the techniques of rehabilitation and the benefits that could accrue from them, I think their attitude would change... He doesn't know anything about therapeutic exercise and gait training and prescribing a short leg brace or training a patient to take care of his needs and learning to talk

> again and learning to control his bowel and bladder. In time the physician population will at least have an awareness of what rehabilitation can offer and will make more referrals.

In other words who the professional is, is important when we are comparing patient and professional views on this topic. The discrepancy of views will probably be widest when the professional is a general practitioner, who may be thinking of inability to reach normality. The patient may be thinking of lesser goals - any improvement is a step forward.

The issue of the elite versus the minimally improvable patient, is probably closely connected with these other critical situations: when to admit and when to discharge.* Many of those who said that unpromising patients should be admitted for a "fair trial", specified a time limit of some weeks, but the adequacy of this standard was questioned:

> It's such a hard judgment problem... Sure you can say if you have a patient here for two months--well you've given him a pretty fair trial... But many times you'll find... the patient is not making any progress, so we have to discharge him, and we can't get him into a nursing home for a month. And in the month, while we're waiting they begin to make progress. Well, if we could have just discharged them then, we never would have seen this. So then we cancel the discharge. Well, how many of these are we sending off before they've shown the improvement that they would have shown if we would have kept them?

There are, then, a number of aspects to be taken into account in approaching the question of candidates for admission to rehabilitation facilities. It is certainly not so simple as this medical student believes:

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*Some of the other things to be considered with respect to time of discharge are: financial strain on patients; the phenomenon of hospitalitis (being frightened of going back into the community and resuming responsibility for oneself); the change in the concept of the professional's job when the patient has plateaued and it is a question of maintenance; the time lag between a patient's reaching a peak and the time when other agencies find a place for him.

> Well, unfortunately, P M & R (Physical Medicine and Rehabilitation) being what it is, understaffed, I think, to expedite matters, the only thing to do is shove those people off the boat and make room for some more. How much time can you devote to a patient?... If they don't benefit from three or four weeks, get rid of them.

Placement After Discharge

One of the difficult critical situations encountered, is that concerning placement of severely handicapped patients after hospitalization - whether to try to have him return home or whether to seek some alternative. Since the family is part of the client constellation in this situation, family members will have to be added as subjects. Patients and professionals outside of the setting of a rehabilitation hospital, would also be desirable as subjects to complete the investigation on this topic. Further analysis of the material on hand, however, will be of considerable benefit to such a future investigation. Some of the dimensions of the problem can, even now, be indicated.

The problem of what to recommend after discharge, was the most frequent subject of discussion at staffings. At Schwab, the order of preference is this: to have the patient go home, if this is possible; to try for independent living, if there is no home to return to and the patient is able to function independently. A room and board situation is the next choice (when the patient is not quite capable of making it on his own). A nursing home is suggested almost as a last resort. Only institutions like State Hospitals are less favorably regarded.

1. The nursing home alternative

The nursing home was usually the least favored alternative when placement was being considered by the subjects of the pilot study. It is called "the end of the line", where patients will no longer "retain their individuality." The best nursing homes were said to be very expensive or to have long waiting lists. Most are considered just custodial, so that the gains made during rehabilitation may not be maintained. The profit motive, according to nurses who have worked in nursing homes, leads to "short-cuts" and "cheating on care." It is said that patient motivation drops as soon as he is told that a nursing home placement is being considered. The patient becomes confused in unfamiliar surroundings, cross and miserable because he feels unwanted, and resentful of being mixed with patients who are senile, when he is only disabled.

Frequently, there are anti-rehabilitation forces at work in a nursing home. Nursing home nurses have said that when they attempt to let patients be a little independent in self-care, the family would see patients whose hair is not exactly tidy or whose clothes are improperly buttoned. "Then they would think we were not giving the service we should." When eating in the dining room was introduced for exercise and socialization:

> I had the most irate woman, that I had dared to take her mother to the dining room... She had earned her rest... What she was really saying was that if mother was capable of becoming reactivated in this way, how could she explain to her social set that she had abandoned mother to the nursing home... If you decide what is best for mamma, the daughter has only to say, "Well I will take her across the street to another nursing home where they will do what I want" and now you have lost a paying patient.

2. Other alternatives

Knowledgeable professionals frequently express a wish for more varied types of intermediate facilities, but they at least know of some alternatives to nursing homes, (room and board situations, for example). Where there are deficiencies in the social service adjunct, this may not be true. A student nurse remarked:

> This rehabilitation hospital, I feel they do very well in this area... They plan before the patient leaves where he can go... Some places just don't have this available ...because they don't have the financial support that can help them out in this area. And so the patients suffer... It is so poor in most institutions.

3. Reasons for placement outside the home

The most obvious reason for placement outside the home is the situation of there being no family to return to. Another reason frequently given is that the patient will not be happy where he is not welcome:

> (If) there's like total rejection at home, well this isn't going to be a very good situation to put him in anyway. So you'd have to find another solution, whether it's a foster home or something like this. Because to go back in an environment where everyone feels very negatively about you, they make this person feel like nothing. So, that's no good either.

The welfare of the rest of the family was, of course, considered. We have referred, in the chapter on independence, to the fact that professionals take into account the larger unit and refer to the fact that having a disabled member in the home may "disrupt" the family. Having to have someone always at home may be too great a burden, or requiring "four to care for one", is not justified. The wide range of feelings involved in being a burden and having another who is a burden to you, is a problem which is more acute after discharge from hospital. It would therefore be profitable to have as subjects, disabled persons some years after hospitalization as well as members of their families. Professionals outside of a rehabilitation setting must also be interviewed on this topic, for it is possible that elsewhere the professional may feel even greater responsibility to the family and put their needs first. Often, the family is seen as the client. This patient spent many years in a nursing home before she was referred for rehabilitation, and now she feels differently, but:

> At first I was mad at him (the doctor). I thought he was thinking more of my daughter than he was of me.

To the extent that that the disabled patient and the family differ in their ideas about placement, there are bound to be difficulties in the relationship between the professional and one part of the client constellation.

A fourth reason for placement outside of the home has to do with anxiety of the family about how to help the severely handicapped. Families are reluctant to accept disabled members at home because of their lack of knowledge about what the handicapped member can do for himself and about just how they are to handle him. In the setting studied, a conscientious effort is made, while the patient is still hospitalized, to relieve the anxieties of the family on this score by demonstrating the patient's actual capacity and by acquainting them with methods of assisting him. Week-end visits home are also important in this regard.* And follow-up visits by therapists to see how the patient is functioning in his own setting, were often recommended.

Again, it is important that professionals outside of such a setting be added as subjects. For when specialists in rehabilitation are not involved, the professionals' lack of knowledge means that the family cannot be properly informed, and this may lead to nursing home placement.

As a vocational counselor complained:

> His wife feels that he's not going to be able to do any of these things... The doctor said that he never could...the family usually takes up the attitude of the family physician...

And an inspector of custodial facilities states:

> There is too much thought among the G.P. a stroke is a stroke and this is it. Now either they are going to be good enough to go home with their wife...and if not we'll send them to a nursing home.

Our understanding of the problems in this area of concern is far from complete. We have indicated that investigation outside of the rehabilitation hospital setting will eventually be necessary. At some time, it might be desirable to compare viewpoints of medical professionals who are, and are not, connected with a rehabilitation center. Some possible advantages of being connected with a rehabilitation center are the following: The professional in the rehabilitation setting has the assistance of a number of other specialists in evaluating the actual capacities of the handicapped person. The information-giving activities of these other persons mean that anxieties, due to lack of family knowledge, play less part in decision-making. Acquaintance with alternatives other than nursing homes means a wider range of choice. Such a professional can call upon others especially trained to handle the guilt that families frequently feel when the decision is not to accept them at home. All this should minimize professional-client difficulties related to the question of placement.

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*Some insurance companies do not permit week-end visits home. It would seem extremely important that they be informed of the very practical advantages that would be gained from changing this policy.

This by no means exhausts the list of critical situations already encountered. These four were discussed often enough that we were able to give a preliminary picture of what can be anticipated from intensive analysis.

Investigation of Determinants Underlying Reasons for Choices

We have had occasion to refer to ideologies which are taught to students or which seem to be a consequence of the "atmosphere" in the particular institution in which this research was carried out. There are other ideologies which affect answers to the various questions, ideologies which seem to stem from the general value system of the individual interviewed. Our analysis of data commenced with a consideration of topics, rather than a consideration of the whole record of an individual. Nevertheless, some observations suggested that using individual records as a point of departure, would be desirable.

As an example, analysis of the record of a recreation therapist showed constant reference to the value of human dignity in disparate situations. Whether the topic under discussion was behavior of professionals on ward rounds, or one of the critical situations, the reason given for advocating particular courses of action was that the opposite leads to "depersonalization" and the client feeling "less important, less human, less worthy".

Similarly a patient illustrated how one dominant value can influence answers to a variety of questions. This patient, in giving reasons for his choice in a number of critical situations, constantly invoked the notion of status. He does not devaluate himself because of his present condition, and will not accept a subordinate status in his relationship with professionals. He says that professionals "cannot demand respect, it must be earned." And "respect is a two-way street"; professionals must show respect to him if they want to be respected. Lack of involvement on the part of professionals was to him an indication of devaluation - of treating a patient like "a thing and not a person." He wanted to be fully informed about his condition because "I am a man, and I should know." On the subject of control, his viewpoint was: "Let me decide, not you." And "even though he is a patient in a hospital, they should have their rights and privileges."

As a further indication of the potential usefulness of this line of attack, we can compare some ideologies which are in marked contrast. The pair of subjects described below are medical students. Both are male and white and 23 years of age, had just completed their first year in medical school and had recently entered upon a summer of clerkship at the hospital. It may be objected that it is relatively early in their careers, and that many of their values will change with more experience. While this might be true, still the different attitudes exhibited can be found in experienced practitioners.

For ease of comparison, the contrasting attitudes are given in parallel columns. The left-column student has an ideology similar to that of the recreation therapist, in that he gives primacy to the value of the individual. The other student does not exhibit this attitude. When the question concerned what to do about the patient who can profit only slightly from rehabilitation, a possible conflict of interests--the individual's versus society's--was indicated.

In the first student, there is a strong feeling that society owes something to the unfortunate members, that we shouldn't count the cost, and that even if no improvement, but only maintenance of a given state can be achieved, it is still worth the investment.	In the interview of the second student, the feeling is conveyed that many people are trying to "sponge" off society; that the cost is to be taken into account, and that the time of trained and scarce personnel is too valuable to be devoted to those who can't or won't profit much, so "get rid of them."

In their attitudes toward control and decision-making, both begin with a positive attitude toward control for the professional.

This student is more critical of his own attitude; he feels that medicine gives "a little bit of a God complex" and "you aren't always right." Yet, he carries control farther because of a strong feeling of responsibility to the individual. "The doctor has to decide if the patient is going to be safe walking with a cane instead of being in a wheel chair." He recommends enlisting the spouse "so if he doesn't want to take his medication, there's the possibility of this second party putting pressure on him."	The issue is less problematic for the second student; he is more apt to wash his hands of the matter. He believes "the patient doesn't have the knowledge or the experience. I think it's very necessary for the physican to maintain control of the situation--to guide it and direct it". Still, "the physician's responsibility ends when he tells the patient just exactly what he should do... You're a diabetic, take insulin. If I were you I'd take the insulin. If you don't, you're going to die. You do what you want to."

Their attitudes toward control were closely tied in with their attitudes toward involvement.

One student not only demonstrates involvement by listing many ways in which he would go out of his way to see that the patient carried out his instructions, he also meets all patients with sympathy: "If he thinks that you feel he's just another patient and another 15 minutes out of the eight hours, it's very bad. The patient has got to think you sincerely sympathize with his situation, sincerely wish for him to get better and that you are doing everything you can possibly for him... not as a cold number but as an individual... So objectivity in decisions and subjectivity and emotional ties with the patient in care, in handling him, in talking to him..."

The student who limited control to just "telling the patient what he should do" stated that "only an odd physician would involve himself more than that because--well it's only another headache, aggravation." Compassion is only for those who are dying. "You're not concerned if you make the patient uncomfortable and you aggravate him. So what! If it's going to help him... Whereas, if a patient is dying, you have no goals for him. There's nothing you can offer him other than sympathy and compassion."

Contrasting ideologies were apparent in other topics also, for example, regarding placement:

The student with strong feelings about human values, would express his disapproval of a family who could take a disabled member home but refuse to, and he would feel some responsibility for allaying the guilt feelings of those who really cannot accept the patient.

The second student would not enter into family decisions about patient placement because "it's not medicine."

The approach via analysis of the individual record as a whole, should aid our understanding of the relationship between critical areas. We have seen some of the interconnections between problem areas in preceding chapters, for example: Hope influences motivation for working toward independence, and a patient works harder for an involved professional. A professional may avoid involvement when his expectations of success are slight. Involvement is sometimes seen as imperiling control. Control seems to be necessary for safety, but is contraindicated by a desire to foster independence. The approach via the record of the individual subject, should enable us to go farther in conceptualization and mapping out connections between problems. We should determine whether there is another level underlying the multiplicity of "reasons" for professional and client choices in critical situations, whether some general values influence many specific choices. Human dignity was one general value encountered. Truth, life and health, self-determination, warm interpersonal ties, making a contribution to society--these were others. And we can expect to find more. They may conflict with or reinforce each other. Which are given most weight by an individual?

Furthermore, values are but one of the possible determinants of choices. Knowledge and belief and needs are others. While there is ample evidence, already, of the existence of these determinants, the relationships between them could not receive sufficient attention during the pilot period. This task is seen as an important next step in the program. It is one of the theoretical aims of the investigation to map out connections between the various critical situations and relationships between determinants of critical situations.

Critical Situations in Other Settings

Another important task is to determine whether the findings and the recommendations arrived at in the pilot study, are limited to the particular type of relationship studied (hospitalized patients with medical or para-medical professionals). Some of the critical situations with which we have been concerned, will be encountered in almost any relationship in which one partner is presumed to be an expert and the other is the one for whose benefit the relationship exists. The issues of personal involvement and control, for example, would exist in relationships between teacher and pupil, as well as in a number of rehabilitation areas where the client might be the retarded, the aged, the delinquent, or the mentally ill. Modifications of recommendations may be necessary to take account of differences in circumstances. Only by studying different types of relationships, can we be sure which are generally applicable.

At the same time, each type of relationship studied can enlarge our roster of critical situations, because certain kinds of critical situations may be especially important for that particular relationship. For instance, in the mental health field, a crucial question might be: whether or not the professional has a responsibility to ferret out those who might possibly do harm and bring them to the attention of the authorities. The question of betraying confidences of a client "for his own good", was encountered in the current study. It is likely to be even more potent in other areas.

A vocational rehabilitation setting might be a good choice for further investigation. Vocational counsellors have as clients the physically disabled and also persons handicapped in other ways. One new critical situation in this area is the following: whether to disclose the existence of a handicap to a prospective employer. This is a significant question when the handicap is one which can be hidden (e.g., a cardiac condition or epilepsy*).

Investigation of Views Promoted by Teaching Personnel

There is still another direction which further research can take. This is particularly pertinent to the practical aim of improving training of students. The pilot study showed that there are sometimes great discrepancies between what students in different institutions are taught about the issues in which we are interested. For example, it will be recalled that some nursing students said that they were taught that it is desirable to become personally involved with patients, while others said they were taught exactly the opposite. Instead of relying on reports at second hand, it would be desirable to ascertain the viewpoints on critical situations, of instructors in representative institutions (medical and nursing schools). Whether or not these viewpoints are deliberately taught, they are still conveyed to students. In addition there can be discussion of what is formally taught to students about professional-patient relationships.

Long Range Research Programs

It has been our contention that the field of professional-client relationships is so full of problems, that many approaches are required. The approach we have selected, via critical situations, will require the attention of many investigators. We recommend it as a fruitful one. The limits we have deliberately set, must not stand indefinitely.

First, this investigation was limited to professional-client relationships in the area of rehabilitation of the physically handicapped. Those working in other rehabilitation areas, or even with very different types of relationships, such as that between subordinate and supervisor in industry, might find the approach a useful one.

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*Some of the same determinants will be found when the client is an ex-convict or a former mental patient.

Secondly, we have emphasized qualitative investigation. We have felt that clarification of *what* it is desirable to quantify, and what basis for selection of subjects is most relevant to particular problems, must precede the use of sophisticated statistical techniques. It is hoped that students looking for thesis problems, will find this qualitative material a fertile source of ideas for problems that can be handled quantitatively.

Third, no attempt has been made to investigate *behavior* of clients and professionals in actual interactions. We have felt that beliefs about why one or another course of action is correct, can bring about difficulties in client-professional relationships, and that clearing up mistaken beliefs can remove some of these difficulties. Of course, one can act improperly even while upholding "proper" opinions, and so eventually interactions must be studied.

Finally, understanding the reasons why professionals and clients make the choices they do, between alternatives in critical situations, is only one step in a long term program of investigation of how to produce *change* when change is required.

APPENDIX I

Table I - Subject Characteristics

Client Disability	No. of Cases
Leg Amputation (3 bilateral and 1 unilateral)	4
Paraplegia	5
Hemiplegia	5
Arthritis	2
Multiple-Sclerosis	2
Miscellaneous Neurological	2
Total	20

Sex: 11 women, 9 men.

Race: 13 white, 7 negro.

Age range: 18-68 (more than half between 40 and 60 years old).

Marital status: Married - 12, single - 4, divorced - 2, widowed - 2.

Educational status: 8th grade or less - 5, some high school - 6, high school completed - 6, 1 to 4 years of college - 3.

Referral source (as an indicator of socio-economic status): 7 were private patients, 13 were clients of a welfare agency (4 obtaining medical aid only).

APPENDIX I

Table I (cont'd)

Professional Discipline	No. of Cases
Physicians (2 physiatrists, 1 psychiatrist, 3 residents in physiatry)	6
Nurses	2
Physical and Occupational Therapists	4
Social Workers	2
Psychologists and Vocational Counsellors	4
Speech Therapist	1
Recreation Therapist	1
Total	20

Sex: 12 female, 8 male.

Race: 16 white, 3 negro, 1 oriental.

Age range: 22 to 58 (more than half under age 40).

Marital status: 15 married, 4 single, 1 divorced.

Educational status: All save two nurses were college graduates.

Years of experience: Range from one to more than 20 years.

Other: Four professionals were themselves handicapped to some degree (e.g., cardiac involvement, residua of polio-myelitis), and two had handicapped spouses.

APPENDIX I

Table I (cont'd)

Student Discipline	No. of Cases
Medical Students	5
Nursing Students	10
Occupational Therapy	3
Social Service	2
Total	20

Sex: 15 female, 5 male.

Race: 19 white, 1 negro.

Age range: 21-27.

Marital status: 16 single, 4 married.

Educational status: All save the nursing students had college degrees.

Years of experience: 1 to 3 years of professional training.

APPENDIX II

Approach to Subjects and Interview Schedule

Approach to Subjects

The experimenter first obtained a list of patients who, according to screening tests, had no severe speech problems which would interfere with recording, and who were intact enough to understand what would be asked. Then, this list was checked with resident physicians to learn whether there were other reasons which would make interviewing undesirable. (There were two instances.) After this, a visit was made to the patients on the ward to secure voluntary co-operation. At this first contact the patient was told that "We are doing something like an opinion poll of patients which we hope will be useful in helping to train people who are going to work in rehabilitation--so that they will know more about the point of view of patients." This explanation was usually enough to secure their willingness to help, and then an appointment would be made. In two instances, out of 22 approached, the patient refused on the first contact and was not again asked to participate.

Interviews with professionals were interspersed with those of patients. The procedure in the case of professional subjects was as follows: A memorandum from the hospital administration was sent out to all department heads introducing the investigator as a member of the psychology department engaged in a research project, and asking their co-operation in the project which "has as its aim obtaining information to be used in the training of students of various professions contributing to rehabilitation." They were told that she would interview professional personnel and patients on "problems of concern to patients and those in the helping professions." Professionals, and some students, were met informally at lunch or over afternoon coffee. All of those invited to participate willingly agreed to co-operate.

Nursing students were seen as a group for the purpose of securing co-operation. In addition to giving them the information which was contained in the memorandum (see above), they were told that "since our aim is to improve training we would like to get a picture of what, currently, students are taught about handling some patient problems. It would be useful to know which things taught are easily accepted and which are difficult to accept, and what looks very different when the time comes actually to put the teachings into practice".

Interview Schedule

As noted in the text, the following are not questions which were routinely asked of all subjects. This was used as a guide to the interviewer for: (1) topics to cover, (2) manner of introducing a topic when the subject did not himself initiate discussion of it, (3) suggestions for additional questions which might be asked when the subject's answer did not provide enough leads which could be followed up, or when further clarification was desirable.

1. Introduction

After obtaining permission to record the interview, assuring the subject of confidentiality, asking that he in turn not discuss the content of the interview; repeating the purpose of the study and the usefulness of the subject's unique contribution; defining and illustrating "critical situation", pointing out that even one alternative may have positive and negative aspects, indicating the importance of reasons for choices made; checking on subject's understanding of what we are after; the introduction was concluded as follows:

"Now this is a planning year for us and we would like your help even in deciding what problems it would be good to investigate. In other words, I would like to draft you as a co-investigator and get your ideas about what are some of the important problems that patients face (or that nurses, doctors, therapists, etc., face insofar as they concern patients)."

2. Problems seen by subject

"What do you think would be a good choice of a critical situation for us to investigate and learn more about?"

"Is this a situation which you have had to face, or is there some other reason why you think it important?"

"Why is this the best solution?"

(Add other appropriate follow-up questions, especially as to the meaning of important words used. The experimenter should note if reference is made to words like "independence," or "hope," or "safety," so that these topics of major interest to the investigator may be introduced by connecting them with these prior statements. This shows that the experimenter has been attentively listening and taking into account what has been said.)

"Are there other problems that you have been concerned about?" (Follow-up as before.)

(When the subject did not propose a topic which he desired to discuss in response to the opening question, the experimenter would reassure him by saying, "It often happens that they don't occur to people just off-hand, but they may as we go more into these matters, so there will be another opportunity before we finish to make suggestions.")

3. Orientation*

"Sometimes patients express a need for more information about the hospital and the routines", (pause for reply).

"Would a booklet be a good idea? What do you think might be good to include in a booklet on this subject?"

4. Hope and reality

"Sometimes the information desired is not about the hospital routines but about the patient's own condition or what he can expect in the future. What would you say on this topic?"

(The experimenter must follow-up any words like "reality," "hope," "denial," "depression," "avoiding confrontation," "truth," "acceptance," etc., by asking "What does this mean?" "Why is this course desirable?" "Under what conditions?", etc. If a conflict is not indicated, then state the opposite possibility, at first with the fewest possible words. For example, if "reality"

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*The interviewer's choice of which topic to begin with when the subject did not choose a topic, was based upon the following considerations: Those who do not spontaneously suggest topics are apt to be persons who are "guarding" themselves in some way. The topic of orientation is directed toward external matters and so may not be as distressing as others. (In fact, this is not a critical situation; little conflict is evidenced. The information gathered might be of use to the hospital and will be further analyzed at some later time.) Nevertheless, by asking for suggestions for an orientation booklet, the interviewer gives the subject a chance to feel that he is making a contribution. Meanwhile the interview situation is getting a little better structured and the subject is beginning to feel more comfortable with the experimenter. Also, it is quite possible that he will use some terms which will provide the interviewer with an opportunity to get into the more critical areas.

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alone is mentioned, then say, "and what about hope?" Other possible questions, if required):

(For professionals*): "Well, a great emphasis on a realistic appraisal may tend to diminish a patient's hopes. Is there a conflict between them? . . . Which is more important? . . . Why? . . . What is positive about the other?", etc.**

(For patients): "Some people say it's important to get the facts - just as they are, even if the picture is not too rosy. . . but this may dash people's hopes. . . which is more important? Why? Is there anything good about the other?"

5. Independence

"In general, do you have any recommendations or comments on the topic of independence and dependence?" or

"You have mentioned 'independence.' I'd like to hear more about what this means to a patient and why it is important."

(Other possible questions when necessary or appropriate:)

"Naturally in a rehabilitation setting independence is stressed. Do you think it is over-stressed?"

(For professionals): "Should one promote independence whenever it is at all possible, or are there some times when one should allow a patient to take a dependent role? . . . What are the conditions under which each is appropriate?"

(For patients): "Are there times when it is o.k. or even good to relax a bit and be a little dependent on someone else?"

(Follow-up on what he has said, for instance, if he mentions "for his own ego", ask what does this mean. Or if he mentions "being a burden", try to separate out the implications for the patient and for his family or others in the surroundings.)

"Is there anything at all which is positive about dependence as opposed to being sometimes just unavoidable?"

6. Help Scale

To further the discussion on independence the following device was adopted: the help scale was presented (see Fig. 1, page 126), and the experimenter said:

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*The questions for professionals are asked of students also.
**Dots indicate pause for reply.

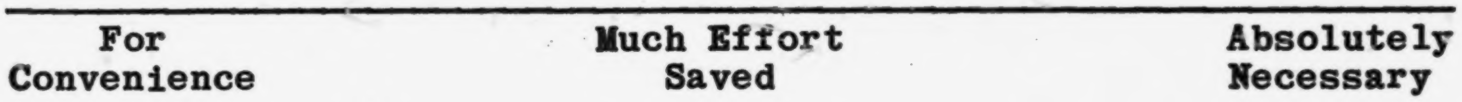
For
Convenience
Much Effort
Saved
Absolutely
Necessary

Fig. 1. Help Scale

"In thinking over this topic we thought that this scale referring to the acceptance of help might be useful. This end is labeled "Absolutely Necessary," meaning that without help you won't be able to accomplish an important task. The opposite end is labeled "For Convenience," in other words, it is easy enough to do something alone, but it may be convenient to accept help. And the middle is labeled "Much effort Saved." In other words, the help of another would represent a considerable contribution."

"Now, thinking of yourself, at what point would you usually be willing to accept help? Make a mark on the line at one of the points or between."

"Would you occasionally accept help at a different point?"

(For professionals): "What would your recommendation be for a handicapped person? Why?"

(To determine the possibility of change if a very strong pro-independence attitude was exhibited):

"During the war I interviewed injured soldiers, and we noted that they frequently said that they wanted help only when it was absolutely necessary. Some even said, 'I mean if there were an earthquake and I couldn't get to my crutches in time.' Now they also said, 'Treat me as you would anybody else, as a normal person.' And we felt that most normal people would not take as extreme a position as this, that at least occasionally they would be willing to accept help for the sake of convenience. So, there was a contradiction here. Furthermore, we thought that there was the possibility, if one took an extreme position, of doing violence to close, affectionate relationships - where the partner wants to do little things for the disabled person, husbands and wives may enjoy some degree of dependence on one another."

(Note acceptance or rejection of this point of view and reasons adduced.)

7. Emotional neutrality and personal involvement

(For professionals): "Is there anything in general you would like to say about emotional neutrality versus personal involvement with patients?"

(Follow-up words like "objectivity," etc. to clarify their meanings further.)

"Many people have told me that in professional training they are warned not to get emotionally involved with their patients. What does this mean and why is it important?"

"Patients sometimes say that professionals are too impersonal - what is it that they want? Why?"

(The question about personal involvement required a different approach for the client group. If they complained of boredom or loneliness, this was sometimes used as a point of departure. Or if there were complaints about their treatment by non-professional staff, they were asked about the professionals. If neither of these openings were offered, then some other patient was quoted:)

"Some patients I have talked to have said that some of the staff are too impersonal or business-like, have you found it so?"

8. Decision-making and control

(If any relevant statements have been made earlier, refer to them. If not, say:)

"Sometimes questions arise about control of events or in whose hands should decision-making rest, what is your feeling on this topic?"

(If a very general answer is given - that of course the patient has to make the "final decisions" of whether or not to accept a professional's recommendation - ask "Why?". Follow-up significant words like "responsibility," "knowledge" - trying to elicit something about the knowledge of the two partners in the dyad. If necessary, ask):

"And how does one insure that the decision is the best one in terms of long-run benefits?" or "Since one can't make him an expert in a short time, how can one guide him as to his own best interests?"

9. Safety and risks

"Sometimes questions arise about playing safe or taking risks." (Pause, this may be enough.)

(If necessary): "When is it best to be cautious, and when are risks justified?"

(If he emphasizes the side of caution, or even warning and then letting the patient decide):

"Have you ever, yourself, wanted to take certain risks feeling, 'Well, I know what the consequences may be but it's my life and if I want to then--' . . . Is it different when you have a responsibility for someone else?"

(Follow-up, especially as regards "position" words like "in my role as a therapist".)

"Is the opposite sometimes true - that patients are too fearful and one has to urge them to try?"

(Note and follow-up anything on the subject of motivation or introduce as an additional topic, e.g.):

"One patient told me that even though they may seem not to care, one should push them a little bit, not just cross them off the list. . . Does this conflict with what patients say about wanting more control? Or what some professionals say about not thrusting independence on people who really don't want it?"

10. Minimal improvement

(For professionals): "When there is a patient who can be expected to profit only very slightly from admission here, what should the policy be?"

(Follow-up appropriately, or if greater clarification is necessary):

"When the disability is very severe or it is apparent that little progress is being made, what should one's recommendation be?. . . Is it worth-while expending the time and effort or resources for a slight up-grading in A.D. L. (Activities of Daily Living)?"

(Note "position" words, or ask):

"Does this change the concept of rehabilitation?" . . . How does it affect one's ideas about his job?"

(For clients): "Suppose there is only a little that can be done for a person here. Should they take him anyway or leave room for someone they can help more?"

11. Fortune-Experiment

To enliven the interview, the "Fortune Scale"* was presented. (See Fig. 2, page 131) The experimenter said:

"Here is another line we have prepared. Suppose this "F", up here, represents the most fortunate person in the world, and this "U" at the bottom, the most unfortunate, and this "O" is the middle. Quickly and without too much analysis, where would you put yourself on this line? Make a mark."

(For professionals): "Where would you expect a 'typical' patient here would place himself?"

"Now I'll tell you an interesting thing. Most of the non-handicapped people I have seen do what you did - put themselves above the middle and expected the patients to mark below the line. Strangely enough, they don't - only one of the patients I have asked this of put himself below the middle. Now it's true that I seldom see them in the most depressed phase. Also I have no guarantee that this is what they really feel deep down. But this at least shows that they do not want to be considered an unfortunate person. Even though they have just spent almost an hour telling me about their difficulties - and they may be willing to say 'it was unfortunate that it happened to me' or 'When I first came here I felt unfortunate', still they resist taking the unfortunate position that the non-handicapped expect them to take."

(Note acceptance or rejection or other comments for clues to the possibility of change of attitude.)

(For clients: Usually, patients volunteer some explanation of why they marked it as they did. If not, the experimenter asks whether this has changed much since he was first injured or ill. This often leads to discussion of how he feels about his disability.)

12. Other problems

"Are there other problems you think it would be good to discuss? Like the problems of placement - institution or home? Family attitudes? Vocational matters?"

(At various times other topics were introduced because of

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*This experiment was suggested in "Adjustment to Misfortune", (3). The analysis of this material and of the help-scale has not yet been done and is not reported here.

Fig. 2. Fortune Scale

something the subject himself said along the way, or because another subject brought it up and it was being tried out as a candidate for inclusion.)

13. Personal data

At the end of the interview some personal data were gathered in the following way:

"Now I don't know yet on what basis we may wish to divide this, age or sex or whatever, so let me get some information about you. You are of course female (male), and...your age is? Marital status? Education?

(For professionals):
Profession, and years of experience?
Were you ever handicapped yourself or spent any great length of time in a hospital?
Was anyone close to you handicapped?
How did you happen to become interested in this career? Was there a family tradition, for instance?

(Information regarding nature of client disability and referral source was obtained from hospital records.)

And finally, in concluding the interview, the subject was given a last opportunity to bring up other problems:

"Is there anything else you would like to add, anything that we did not cover adequately?"

He was then thanked for his help and there was usually some informal conversation. During this time subjects usually expressed great satisfaction with the interview experience, or said how much this needed doing. Professionals asked to know plans for future work and whether they could be acquainted with the results when obtained.

APPENDIX III

Table II - Frequency of Topics Brought up Spontaneously by Subjects in Interviews

Topic	Clients	Professionals	Students	Total
1. Independence and dependence	10	7	6	23
2. Hope and reality	5	4	6	15
3. Involvement and emotional neutrality	5	5	5	15
4. Relationships between professionals (e.g. the team approach)	0	11	4	15
5. Orientation to the hospital	2	6	2	10
6. Control and decision-making	4	5	0	9
7. Dignity of client (e.g. on ward-rounds, exposure of body)	3	4	2	9
8. Lack of knowledge of rehabilitation (especially in general practitioners)	3	4	2	9
9. Motivation	2	6	1	9
10. Miscellaneous communication problems (e.g. about medicines, appointments, etc.)	6	1	1	8
11. Non-professional staff (e.g. need for more in-service training)	2	2	4	8
12. Time of discharge from hospital	0	6	1	7
13. Patient to patient relationships	6	0	1	7
14. Family attitudes	1	4	2	7

APPENDIX III

Table II (cont'd)

Topic	Clients	Professionals	Students	Total
15. Vocational problems	3	3	1	7
16. Boredom, loneliness	3	1	2	6
17. Candidates for rehabilitation (the elite and the minimally improvable patient)	0	5	1	6
18. Placement problems (e.g. home vs. nursing home)	1	3	2	6
19. Professional non-appreciation of client difficulties	3	2	1	6
20. Financial troubles of client	1	3	1	5
21. Exploring and helping the professional with his attitudes toward disability	0	3	1	4
22. Miscellaneous problems regarding professional training (e.g. lack of psychological training felt)	0	1	3	4
23. Keeping confidences of client	0	2	2	4
24. More follow-up desired	0	4	0	4
25. Safety and risks	4	0	0	4
26. Regression after discharge	0	3	0	3
27. Insurance companies which do not permit week-end passes	1	2	0	3
28. Problems with wheel chairs	2	1	0	3
29. Sex problems	0	2	1	3
30. Rehabilitation centers vs. rehabilitation units in hospitals	1	2	0	3

(Problems mentioned only once or twice not included.)

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